NATIONAL ME/FM ACTION NETWORK
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Quest
Newsletter

www.mefmaction.com Quest 145, Spring 2025 mefminfo@mefmaction.com

Redesigning ME Health Care

The Story

For several decades, the prevailing theory for Myalgic Encephalomyelitis (ME) held that people could get better with effort and exertion. ME health care systems were designed around that theory. Graded Exercise Therapy (GET) was recommended. Little other health care was offered.

This prevailing theory has fallen out of favour. The US Institute of Medicine (IOM) rejected the theory ten years ago. The current theory is that over-exertion (physical, cognitive, emotional or social) can negatively affect the health of people with ME, even permanently. Avoiding over-exertion would lead to better outcomes for individuals. ME brings with it a substantial burden of illness and the overall benefits to society would be significant.

In 2021, the National Institute for Health and Care Excellence (NICE), the medical advisory board in the UK, released updated guidelines for ME diagnosis and treatment.
https://www.nice.org.uk/guidance/ng206
The new guidelines recommend against GET for people diagnosed with ME. But then the guidelines go much further than that.

The guidelines recognize that ME often goes undiagnosed and that people without a diagnosis could unwittingly be making their health worse by over-extending themselves. The guidelines therefore recommend that the health system watch for people with possible ME, alert them immediately to be cautious of over-exertion, and then conduct investigations so that a confirmed diagnoses can be made quickly.

Contents

The guidelines also recognize that ME is chronic and that people with a diagnosis (whether new or long-standing) need plans for the management of activity and care. These plans should be developed in conjunction with ME specialist teams. Lifestyle adjustments may be needed and this can have implications in areas like social services, schools and workplaces. Further, people should be monitored on an ongoing basis because health and circumstances can change.

The guidelines recognize that ME symptoms can be severe, which has implications for home care and hospital care.

In 2024, the government of Scotland asked the managers of the 14 health districts in Scotland how they were providing services to people with ME in light of the new NICE guidelines. The study found that there are big gaps in ME health care and that the districts are floundering when it comes to fixing those gaps. This shows that health systems need to recognize that harm is being done by out-of-date systems and they need a greater sense of urgency to fix the systems.

While it is easy to criticize Scotland, we should keep in mind that studies would likely find the same situation in many jurisdictions. We should be thankful that Scotland conducted and published this study. There are lessons in it for Canada.

The NICE Guidelines for ME

New guidelines for the management of ME were released by NICE in 2021. New guidelines were badly needed. The guideline authors looked at the old model of care and noted that "*evidence showed a lack of belief about myalgic encephalomyelitis ... as a real condition by health and social care professionals, and a lack of understanding about what it is and the impact it has*". ME had, for all practical purposes, been shut out of the health care system. The new guidelines would make ME part of the health care system.

The NICE guidelines have a section written for the general public describing ME and the health and social care people should expect – see below.

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Information for the public

ME/CFS: the care you should expect

Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) is a long-term condition that affects about 250,000 people in the UK. It can cause many different symptoms, which can be triggered or worsened by any kind of effort or activity. Symptoms include flu-like malaise, sleep difficulties, brain fog and a profound fatigue that is unlike normal tiredness. People may also experience chronic pain, headaches, nausea, digestive problems, and sensitivity to light, sound and other stimuli. Symptoms come and go and can change or worsen with little warning, causing distress and disrupting people's lives.

ME/CFS is different for everyone. It can range from a mild illness to a severely disabling one that leaves some people housebound or bedbound. Because it can look like many other illnesses, people often face uncertainty and delays in diagnosis. There are options that can help people manage their ME/CFS, but a therapy that helps one person may cause harm to another so a carefully tailored plan and specialist advice is always needed.

We have updated the 2007 version of this guideline using the best available research and working with people who are affected by ME/CFS and professionals who treat and support them. We want it to make a difference to all adults, children and young people with ME/CFS and their families and carers by:

- helping doctors recognise when someone's symptoms could be ME/CFS
- making it faster to get support once ME/CFS is suspected so people don't have to wait for help while other conditions are ruled out
- making sure people with ME/CFS have a confirmed diagnosis at 3 months
- helping everyone with ME/CFS get specialist support and care designed around their own particular needs
- making services more flexible to help people with ME/CFS get the care they need – for example by making home visits, offering shorter or longer appointments and planning any hospital stays around their needs.

The NICE guidelines say that health professionals should suspect ME if a person meets all of the following criteria. Note that ME can be suspected 6 weeks after symptom onset for adults, 4 weeks for children and young people.

Suspecting ME/CFS

Explain to people presenting with possible symptoms of ME/CFS that there currently is no diagnostic test for ME/CFS and it is recognised on clinical grounds alone.

Suspect ME/CFS if:

- the person has had all of the persistent symptoms in box 2 for a minimum of 6 weeks in adults and 4 weeks in children and young people and
- the person's ability to engage in occupational, educational, social or personal activities is significantly reduced from pre illness levels and
- symptoms are not explained by another condition.

Symptoms for suspecting ME/CFS

All of these symptoms should be present:

- debilitating fatigue that is worsened by activity, is not caused by excessive cognitive, physical, emotional or social exertion, and in not significantly relieved by rest.
- Post exertional malaise after activity in which the worsening of symptoms:
  - is often delayed by hours or days
  - is disproportionate to the activity
  - has prolonged recovery time that may last hours, days, weeks or longer.
- Unrefreshing sleep or sleep disturbance (or both), which may include:
  - feeling exhausted, feeling flu-like and stiff on waking
  - broken or shallow sleep, altered sleep pattern or hypersomnia.
- Cognitive difficulties (sometime described as 'brain fog'), which may include problems finding words or numbers, difficulty in speaking, slowed responsiveness, short-term memory problems, and difficulty concentrating or multitasking.

Immediately upon suspecting ME, the health provider should conduct a more throrough investigation for ME and any co-morbidities or for alternative diagnoses. The health provider should consult with specialists as appropriate. The health provider should also advise patients to manage their energy expenditure until the situation is confirmed.

Advice for people with suspected ME/CFS

When ME/CFS is suspected, give people personalised advice about managing their symptoms. Also advise them:

- not to use more energy than they perceive they have – they should manage their daily activity and not 'push through' their symptoms
- to rest and convalesce as needed (this might mean making changes to their daily routine, including work, school and other activities)
- to maintain a healthy balanced diet, with adequate fluid intake.

Explain to people with suspected ME/CFS that their diagnosis can only be confirmed after 3 months of persistent symptoms. Reassure them that they can return for a review before that if they develop new or worsened symptoms, and ensure that they know who to contact for advice.

Confirmation of diagnosis can be made 3 months after symptom onset. That should be accompanied by a referral to a ME specialist team.

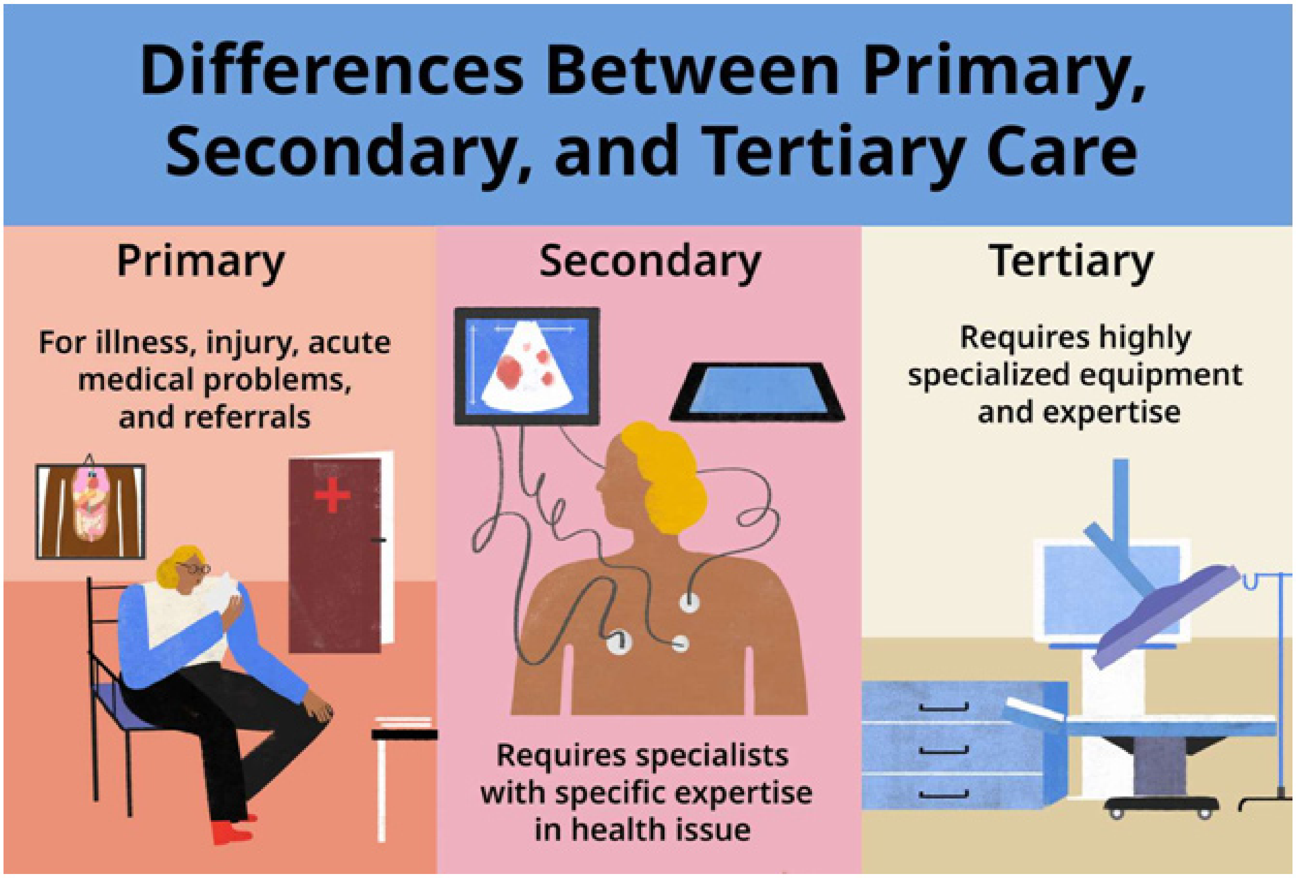
The specialist team should review the diagnosis and develop a care and support plan. Issues that could be covered in the care and support plan can include:

- information and support needs
- support for activities of daily living
- mobility and daily living aids and adaptations to increase or maintain independence
- education, training or employment support needs
- self-management strategies, including energy management
- physical functioning and mobility
- managing ME and symptom management, including medicines management
- guidance on managing flare-ups and relapses
- details of the health and social care professionals involved in the person's care, and who to contact.

ME/CFS specialist team

Specialist teams consist of a range of healthcare professionals with training and experience in assessing, diagnosing, treating and managing ME/CFS. They commonly have medically trained clinicians from a variety of specialisms (including rheumatology, rehabilitation medicine, endocrinology, infectious diseases, neurology, immunology, general practice and paediatrics) as well as access to other healthcare professionals specialising in ME/CFS. These may include physiotherapists, exercise physiologists, occupational therapists, dietitians, and clinical or counselling psychologists.

Children and young people are likely to be cared for under local or regional paediatric teams that have experience of working with children and young people with ME/CFS in collaboration with ME/CFS specialist centres.



Changes Needed to the Health System.

The new guidelines require substantial changes to the health care system.

- Primary care needs to recognize ME cases and to support patients.
- Secondary care needs to provide advice to patients, primary care and other health services.
- The guidelines note that severe ME is real and therefore the tertiary care system (hospitals) need to be involved.
- Because young people can develop ME, the pediatric system needs to be involved.
- The social support system, home care, schools and workplaces also have roles to play.
- Patients need to be aware that they should be contacting the health system when certain symptoms are present, so public awareness is important.

The Scottish Study

Technically the NICE guidelines for ME are not the law in Scotland. There is a separate Scottish Good Practice Statement on ME. In actuality, NICE provides the most current and best guidance on how the Scottish health system should operate.

The population of Scotland is about 5.5 million, roughly the same as the population of British Columbia and one-eighth the population of Canada. The health system in Scotland is divided into 14 regional health districts, each managed by a board.

The Scottish government has undertaken two surveys of these boards. The first survey was run in 2022 and ten of the boards replied. The survey was run again in summer 2024. This time all the boards replied, with several boards simply saying that their 2022 returns were still valid.

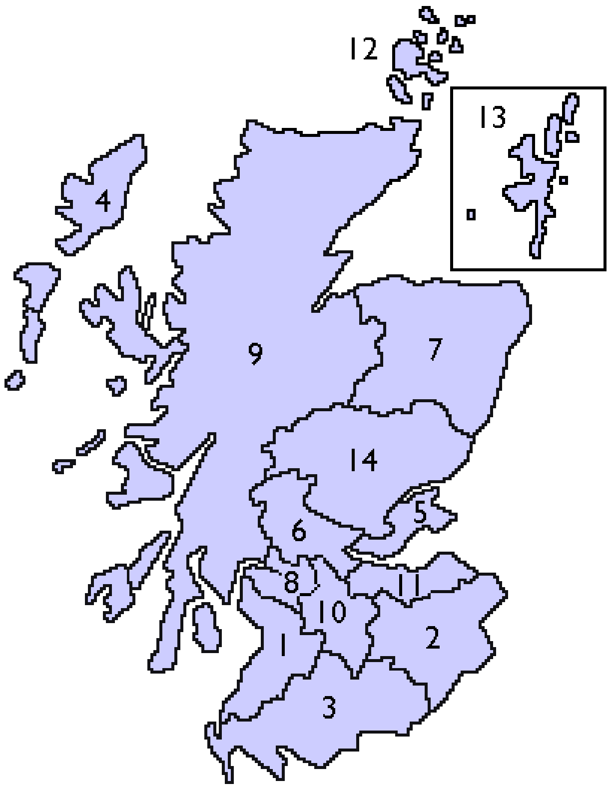
The survey explored these issues:

1. how ME services were being delivered,
2. how the updated ME NICE guidelines were being implemented, and
3. challenges to implementing the guidelines.

Survey Findings

<u>1. How ME services were being delivered</u>

Boards reported that most ME cases were identified by General Practitioners. Other sources include self-referrals and other health care providers. Several cases had even been drawn to a district's attention by members of the Scottish parliament.



Scottish Healt Districts

Where can the GP turn for help in diagnosis and treatment? Only two boards had a ME specific program on their books. (One was run by a nurse and the other by a physiotherapist. The nurse position was vacant at the time of the second survey.) Four other boards said that they had some staff members trained in ME. In the remaining districts, ME patients were sent to generic services - medical specialists (rheumatology, neurology, cardiology, psychiatry, etc), allied health professionals (occupational therapists, physiotherapists, dieticians, etc) or community groups.

Physiotherapists provided support in 12 of the 14 districts. Occupational therapists and nurses provided support in 11 districts. Doctors provided support in only 10 of the districts.

All districts offered care in person. Most but not all districts offered care by phone or video.

2. <u>How the updated ME NICE guidelines were being implemented</u>

When asked "How aware NHS Boards are about the NICE guideline changes about Graded Exercise Therapy (GET)", ten boards stated they were very aware, two said that they were moderately aware, while two boards did not give a response.

The NICE guidelines state clearly “Do not offer the Lightning Process, or therapies based on it, to people with ME/CFS”. (The Lightning Process requires tolerance of exertion.) One district reported the lightning process is a service it offers, even though it also answered that it was very aware of the guideline changes around GET.

3. <u>Challenges to implementing the guidelines</u>

In the first round of the survey, the boards identified several key challenges to improving health care:

- outdated professional and public views about ME/CFS,
- resourcing and funding, and
- legacy waiting lists.

The second survey found the same three issues, but boards went into greater detail around resourcing and funding. They noted difficulty recruiting staff with specialist skills, limited staff capacity for training, and challenges serving the severe/very-severe community.

By the time of the second survey, Long COVID had become an issue. Boards had mixed feelings around combining ME care with long COVID care. On one hand, they said that dedicated long COVID funding improved the scope of services available to people with ME/CFS. On the other hand,some districts raised concerns that this new focus could lead to staff re-deployment, unsustainable services or inequity in service provision depending on an individual’s condition. It was also pointed out that withdrawal of the Long COVID stream of funding could have negative consequences for ME/CFS provision.

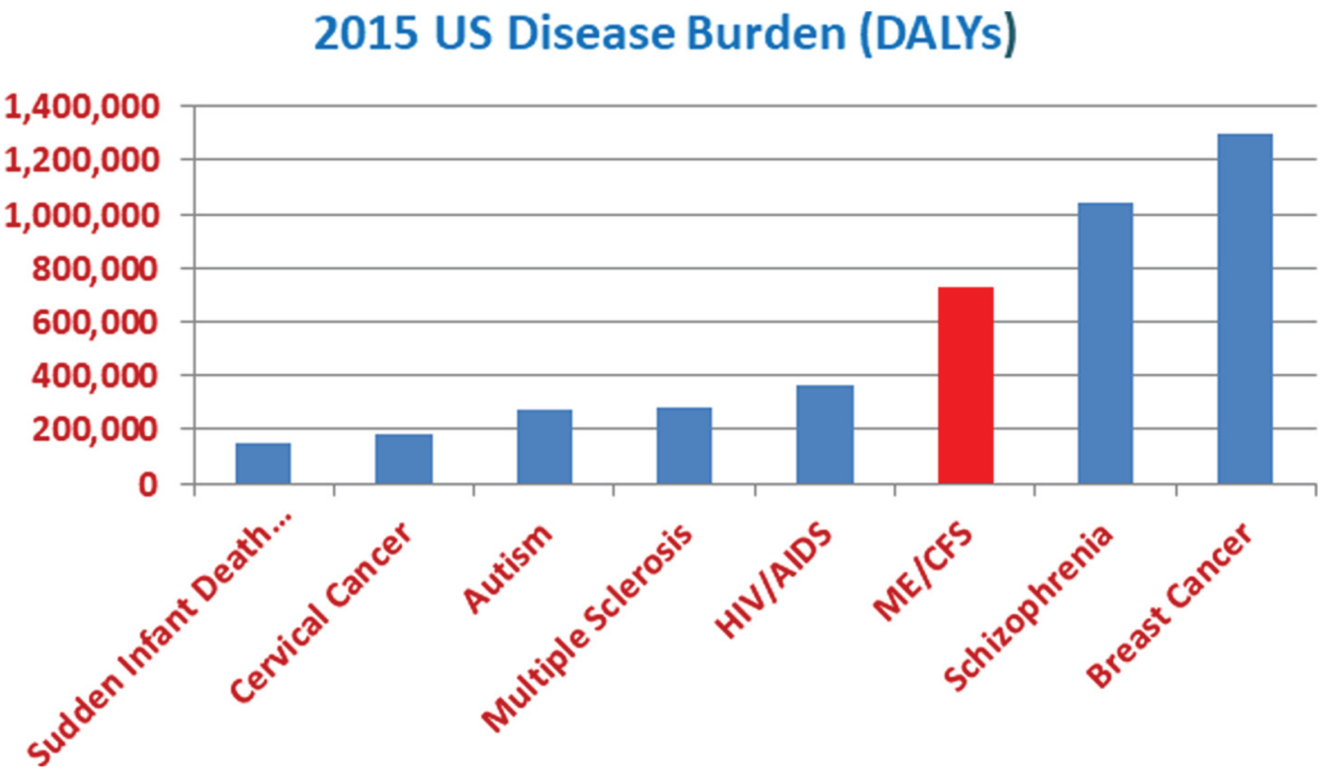


Figure 1. The US disease burden of ME/CFS relative to that of well-known, impactful diseases.

Observations

The patient advocacy group #MEAction Scotland, made this comment on the 2022 findings: "*The survey results showed that implementation of the NICE guidelines across Health Boards varied from sparse to non-existent, due to a lack of capacity, knowledge and resources.*"

The 2024 Scottish government report made this observation: "*The results of this survey highlight a willingness of the NHS boards to develop ME/CFS specific treatment and support, yet there is an acknowledgement that better understanding and awareness of ME/CFS, investment in training capacity and sustainable service design will need to be addressed first.*"

Lessons for Canada

The NICE guidelines removed Graded Exercise Therapy as a treatment for ME. They also recognize that over-exertion can cause harm for people with ME, even people unaware that they have ME, so they recommend early diagnosis and ongoing support to reduce the possibility of harm.

ME brings with it a substantial burden of illness. The Canadian Community Health Survey shows that the ME (chronic fatigue syndrome) community has high rates of needing help with tasks, mobility problems, cognitive problems, pain, and inability to work. Meanwhile, they make frequent visits to health care providers but come away unsatisfied. (See *http://mefmaction.com/docs/CCHS_2005-2014_Tables.pdf*) Evidence also comes from a series of US studies that combine years lost through premature death (mortality) and years lost through reduced functioning (morbidity) into DALYs (Disability Adjusted Life Years). The table on the previous page was taken from *https://content.iospress.com/articles/work/wor203173* and shows that the disease burden of ME/CFS is about double that of HIV/AIDS and over half that of breast cancer. This illustrates that ME/CFS impacts Americans to an extent comparable to that of other major diseases.

With such a significant burden of illness, one would think that health systems would welcome changes that would reduce the burden. But, as the Scottish study shows, health systems find it easier to identify barriers to implementing the needed changes rather than actually making the needed changes.

We have encountered the same inertia in Canada. For example, a task force in Ontario provided an excellent set of recommendations on how to improve health care for ME, FM and Multiple Chemical Sensitivities in 2018 *https://files.ontario.ca/moh-task-force-on-environmental-health-report-dec-2018-en-2023-03-09.pdf* This was followed in 2021 by a report on how to implement those recommendations, but the later report has never been released and little action has been taken. (This brings up an issue not discussed in the NICE guidelines or in the Scottish study. Should new systems be developed for ME alone or for overlapping, related, underserved conditions.)

In summary, the idea that people with ME can get better by pushing themselves has been discredited. Exertion can cause people harm. The health system should not recommend exertion as a treatment for people diagnosed with ME. Further, possible ME cases should be identified early and people should be advised not to push themselves. Support should be ongoing. This will lead to better outcomes for individuals and a lower burden of illness on society. This requires changes in the health care system. The system has been slow to respond. A much greater sense of urgency is needed.

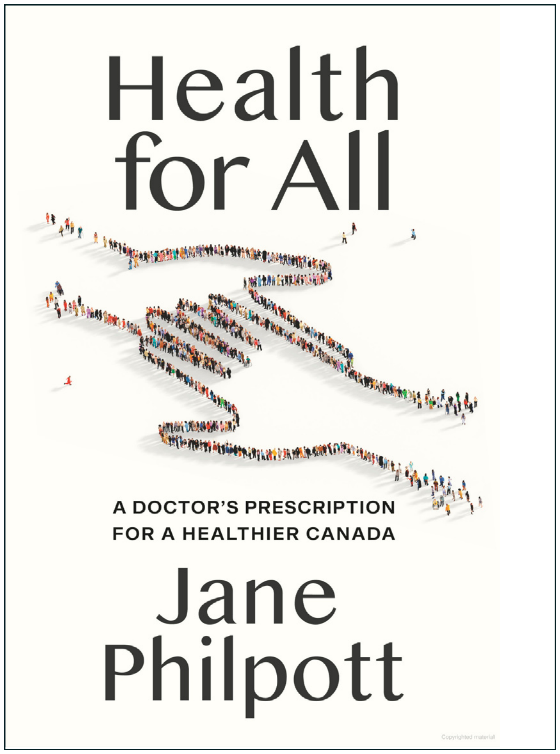
Redesigning Primary Care

There is a crisis in primary care in Canada. Many people find themselves without a doctor or nurse practitioner to monitor their health. What can be done about this?

One problem is that there is a larger demand for family doctors and nurse practioners than the supply available. A proposed solution is to hire people from outside Canada and to qualify them more quickly.

Dr Jane Philpott approaches the primary care crisis from a different direction. Key in her approach is making primary care a more desirable profession and more in tune with community needs. Dr Philpott is a primary care doctor who has worked in Africa and in Canada. She was a Canadian Member of Parliament from 2015 to 2019 and served as Canada's Minister of Health from 2015 to 2017. She was Dean of the Queen's University Faculty of Health Sciences from 2020 to 2024.

In spring 2024, Dr Philpott released a book called *Health for All: A Doctor's Prescription for a Healthier Canada*. In October 2024, Dr Philpott was appointed by the Ontario government to chair a task force on connecting Ontarians to primary-care doctors within five years.



Her book talks about the problems in Canada's primary care system. She observes that older doctors are leaving and younger doctors are not taking their place. She proposes ten possible reasons why doctors may shy away from specializing in family practice. She starts with medical school training and goes on to raise issues around working conditions. Pay particular attention to her fifth point.

1. Medical schools train people in many types of medicine (family medicine, oncology, pediatrics, cardiology, psychiatry, radiology etc) and may not be selecting enough students who are interested in family medicine.
2. Medical schools may be signalling that other specialties are a better career choice.
3. There may be a gender effect. With women entering family medicine, students may see family medicine as less worthy than other areas.
4. With many topics covered in medical schools, family medicine may not get sufficient attention.
5. **Family medicine is difficult. It is hard to diagnose undifferentiated conditions or manage complex, chronic diseases. Family doctors must excel at managing uncertainty. Students may prefer to become experts in narrower fields of practice.**
6. There is a pay gap between family medicine and other specialties.
7. Family medicine has non-stop responsibilities.
8. The conditions of work may be unattractive. Family doctors run a small business with administrative challenges.
9. Specialists who work in hospitals have other health professionals with them, while family doctors do not receive funding for an interprofessional team to share the workload.
10. Patients may visualize family doctors as people who refer them to specialists and not as medical experts in their own right.

Dr Philpott's vision is that everyone would have a 'primary care home' consisting of a team - doctors/ nurse practitioners, allied health professionals and support staff. The team would be obligated to accept anyone living in their designated area in the same way that public schools must accept all student living in their area. People would sign up with the primary care home and not with a specific doctor. Their care would be coordinated among the team.

This model could be of great help to people with ME and/or FM because it aims for universal access to primary care and it also builds in multi-disciplinary supports. But this model will work for the ME/ FM community only if certain conditions are met, including:

- **the primary care home has the medical skills to recognize and manage ME and FM cases,**
- **the primary care home has access to secondary and tertiary supports to meet people's ME and FM needs, and**
- **the primary care home receives sufficient resources to deal with ME and FM cases.**

This means that ME and FM must be considered in the development of the primary care home model.

The Federal Election

A federal election is scheduled for April 28, 2025.

The National ME/FM Action Network is a non-partisan organization. We are not going to suggest for whom you should vote in this election. But we are going to suggest that this is an opportunity to raise issues with candidates - like the need for better ME/FM health care, for more ME/FM research and for better access to disability supports.

We encourage everyone who is eligible to vote to do so. (You must be a Canadian citizen, age 18 or older and provide appropriate identification). We discussed methods of voting in detail in Quest 104 (2015). Here are some key points.

Where to vote (outside your home):

- at your local polling station on election day
- at an advance poll 10 to 7 days before the election
- at any Elections Canada office until a week before the election

You can get information about locations from Elections Canada or from any of the candidates.

Some suggestions:

- if you need a drive, you can ask a candidate
- if there is a line-up, you can ask for a chair
- you might want to take earplugs in case the location is noisy
- don't forget your ID.

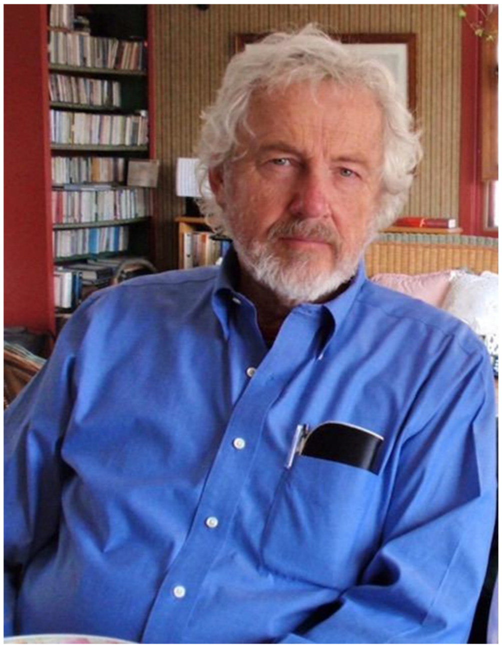
If you can't get to one of these locations, you can still vote using a special ballot

- that you mail in
- that Elections Canada brings to your home, you fill it in and they take it away

Some suggestions:

- contact Elections Canada early to make arrangements – you can't arrange special ballots at the last minute
- a candidate may be able to help you with the logistics
- if someone is coming to the house and it takes you time to get to the door, let Elections Canada know to wait

Remembering Dr. Byron Hyde



Byron HYDE MD August 8, 1936 to November 17, 2024

Dr. Byron Marshall Hyde studied pre-medicine in the Faculty of Medicine, University of Toronto in 1961. He graduated from the University of Ottawa Faculty of Medicine in 1966.

After an internship at Montreal's Hotel Dieu and residency at the St. Justine Paediatric Hospital and the Ottawa Civic Hospital, he opened a family practice in Ottawa that continued until 1984 when he started the full time study of post infectious Myalgic Encephalomyelitis.

Dr. Hyde is survived by his beloved wife, Lone; and his children and grandchildren, to whom we send our deepest condolences. We also extend condolences to Lenka, his devoted assistant at Nightingale Research Foundation. Byron will be deeply missed by all who knew him.

His passing is a major loss to the international Myalgic Encephalomyelitis community.

This obituary was written by the Nightingale Research Foundation and appeared in the Globe and Mail.

President Awarded Coronation Medal

Dear Friends

I am delighted to announce that our president, Margaret Parlor, has been awarded the King Charles III Coronation Medal. This is an award given to people who have made a significant contribution to Canada. She was presented with her medal by Member of Parliament, Anita Vandenbeld.

My first contact with Margaret was over 20 years ago. She was on leave from her federal government job because her family had been affected by ME/FM.

Margaret was already familiar with disabling chronic conditions that are poorly recognized by the health and disability systems. Her sister had autism long before autism was well recognized. The services her sister needed were not in place. Her sister spent her early years at the blind section of the BC school for the deaf and blind in Vancouver. She did not go there because it was the right school for her. She went there simply because the school was nearby and the classes were small.

Margaret got a math degree from the University of Victoria. (She liked to brag that she went to university overseas. You do, after all, have to take a ferry to get to Victoria.) She followed that with a law degree from UBC and had a summer job looking at disability issues. Then she worked at City Hall Port Alberni and City Hall Hamilton. Having moved to Ontario, she needed new licence plates for her car. The plates she was given started with "OTW" which she took as a sign that she was supposed to move to OtTaWa. So she moved to Ottawa. She contacted Statistics Canada, which her friend said was always looking for people. She was hired to figure out what statistics were needed to manage the criminal court system in Canada and then to collect and publish those statistics. She moved on to other interesting challenges, including overseeing the monthly publication of the consumer price index. She finished her career at Treasury Board Secretariat which looks at how government can work more effectively.

Since getting involved with the National ME/FM Action Network two decades ago, Margaret has taken on many challenges. She started by contributing to the first edition of the Teach-ME Sourcebook, then overseeing the second edition incorporating the then new Canadian Consensus Criteria. She discovered the Canadian Community Health Survey, then compiled and published 2005 statistics on ME and FM which showed how much ME and FM were affecting Canadians. She took on the role of President in 2008. She helped host the 2011 international association meeting in Ottawa. She took on editing the Quest newsletter. She took over monitoring of phone and internet inquiries. She helped rewrite the CPP-Disability application and appeals guide. She made a presentation at the 2014 international conference and ran workshops at the 2017 international conference as well as the 2018 Canadian conference. She served on the initial executive committee of the Canadian ME research network. She has examined disability issues and recently prepared a submission to the UN Committee reviewing Canada's implementation of the Convention on the Rights of Persons with Disabilities.

I often say that there are three keys to advocacy – passion, patience and perseverence. Margaret has displayed all three. Her medal is well deserved.

Lydia E. Neilson, MSM
NATIONAL ME/FM ACTION NETWORK

King Charles III Coronation Medal

A person is eligible to be awarded the medal if the person

(a) has made a significant contribution to Canada or to a particular province, territory, region or community of Canada, or has made an outstanding achievement abroad that brings credit to Canada, and was alive on May 6, 2023;

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