CareNow ONTARIO

Laying the Groundwork
Discussion and Next Steps

Surprise release of the “Laying the Groundwork Implementation Plan

How did we get

It Started in 2010

- 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.

2012-13: Blueprint for OCEEH

- 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

2013: blue print for Ontario Centre for Excellence in Environmental Health (OCEEH)

Recognition, Inclusion and Equity: Solutions for Ontarians with ES/MCS, ME/CFS and FM – The Business Case Proposal (Steering Committee of the OCEEH Business Case Project, 2013)

- sequenced, budgeted, costed plan that was developed from the three research documents written to inform the best design.

- 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.

2016 - Government Task Force was established

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 report validated the recommendations in the Business Case.

- **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

2020-21: Implementation Plan

- 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.
- Timeline: 6 months
- Covid hit and the report was not completed until Summer 2021.
- Change of Health Minister to Minister Jones.

- The report was called **Laying the Groundwork**

- Since that time, CareNow Ontario (formerly MEAO) received no response to countless requests for updates and to release of the report..

2022-25: NDP and the FOI request

- In 2022, France Gelinas, health critic, NDP submitted a Freedom of Information request to release the full report
- At one point a redacted report was released. It only had the title, table of content and people that were consulted
- The NDP did an appeal with no results
- They did one final appeal and to our mutual surprise the report was released in its entirety in June 2025 to the NDP

2025: NDP releases it to CareNow Ontario

- The government had no intention to release this report any more than was directed by the FOI commissioner.
- Therefore they only provided the required copy to the NDP.
- The NDP provided CareNow Ontario with a copy of the full report.
- To date the report has only been released to the Friends of CareNow Ontario and our members.

Huge thank you to the NDP

Laying the Groundwork:

Building Sustainable, Robust and Integrated Health Care Services For Ontarians with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Fibromyalgia (FM) and Environmental Sensitivities/ Multiple Chemical Sensitivities (ES/ MCS)

July 2021

Released June 2025

Mandate

- In January 2020, the Honourable Christine Elliott, Deputy Premier and Minister of Health asked Public Health Ontario (PHO) to lead a review of the report of the Task Force on Environmental Health (TFEH) entitled *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)*.

Mandate

- This Report, submitted in 2018, found there was:

  a) little recognition of the seriousness and severity of these conditions;
  b) a shortage of knowledgeable care providers;
  c) a lack of clinical tools to support and guide care; (
  d) a shortage of services and supports for people living with these conditions;
  e) a dearth of research and leadership to improve the management of these conditions as well as health outcomes for those affected; and
  f) a failure to acknowledge the stigma associated with these conditions and its devastating impact on people’s lives.

- The Minister requested that PHO assess the TFEH's recommendations and identify practical real solutions to directly benefit Ontarians, with a focus on
  a) practical next steps where prompt action could be taken, and
  b) actions that were both cost-effective to implement and aligned with the evolving health care system.

- The assessment was to include:
  a) A review of the TGEH Final Report's 10 recommendations to determine opportunities to quickly improve care, with an emphasis on primary care settings;
  b) Advice on the sequencing of potential investments and/or system changes to provide effective and efficient solutions that would directly benefit Ontarians, including:
     a) A plan for early actions supported by options with work plans and cost estimates to be delivered within six months.

- PHO was further asked to monitor the progress of the early actions and report six months post-implementation with an updated plan that included additional actions and proposed options for long-term leadership of this work.

Proposed action plan’s four pillars

The action plan consists of four pillars:

1. a solid foundation and leadership model;
2. emphasis on primary care;
3. evidenced-informed clinical guidelines and information; and
4. research and evaluation.

Recommendation #1- Environmental Conditions Organization (ECO) and Leadership Model for Ontario

TFEH Recommendation #8

1.0 Establish an overarching Environmental Conditions Organization (ECO) and leadership model that is both cost-effective and aligned with the evolving health care system for the purposes of improving health outcomes for people with ME/CFS, FM and ES/MCS.

1.1. The ECO will implement the remainder of the Initial Action Plan, assess and sequence the balance of the 2018 Care Now recommendations.

1.2. The ECO will be scalable from a start-up to a mature organization that will oversee programs for environmental health conditions across Ontario, creating opportunities for future growth (potentially scalable to a Centre of Excellence for ME/CFS, FM and ES/MCS care, education, research and policy development).

1.3 The Leadership of the ECO will establish three main advisory committees to include a community voice and to advise on Primary Care/Clinical Guidelines and Tools and Research and Evaluation Plans

1.4. The ECO will monitor implementation of the Action Plan and address organizational risk and performance.

1.5. The ECO will develop a monitoring framework to measure the success of the implementation of the Initial Action Plan.

#2 – Develop a Primary Care Plan

TFEH Recommendations #1.3, #3, #3.1, #4

2.0 The ECO will develop a Primary Care Plan for Primary Care Providers (PCPs) providing care to people living with one or more of ME/CFS, FM and ES/MCS.

2.1 The ECO will create a structure and process for developing a Primary Care Plan to increase awareness of these conditions in the primary care setting.

2.2 The ECO will create a process for the dissemination and adoption of Clinical Guidelines and Tools for PCPs.

2.3 The ECO in its Primary Care Plan will include a strategy to support a cadre of PCPs skilled in managing ME/CFS, FM and ES/MCS and establish a community of practice to provide training and support a network of PCPs across the province.

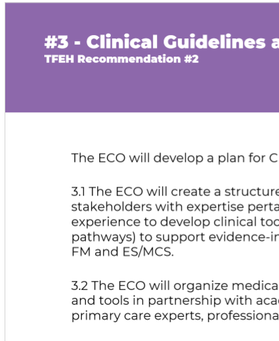
#3 - Clinical Guidelines and Information

TFEH Recommendation #2

3.0 The ECO will develop a plan for Clinical Guidelines and Tools.

3.1 The ECO will create a structure and processes for bringing together key stakeholders with expertise pertaining to these conditions and those with lived experience to develop clinical tools (e.g., definitions, guidelines, and critical pathways) to support evidence-informed treatment and management of ME/CFS, FM and ES/MCS.

3.2 The ECO will organize medical education to facilitate adoption of the guidelines and tools in partnership with academic health sciences centres, patient partners, primary care experts, professional associations and regulatory bodies.



#4 - Research and Evaluation

TFEH Recommendation #7

4.0 The ECO will develop an initial Research Plan and act as a catalyst to encourage research pertaining to ME/CFS, FM and ES/MCS.

4.1 The ECO will conduct an environmental scan to assess the current research landscape.

4.2 The ECO will collaborate with research partners and capitalize on relationships with well-known research leaders.

4.3 The ECO will work with research funding organizations to create a spirit of enquiry, innovation, and evaluation.

4.4 The ECO will develop a process to Identify and closely monitor new research and promising practices to ensure information is readily available to care providers and to update clinical guidelines.

Financial Summary

The annual ongoing and one-time funding for this proposal are as follows:

Table 1: The proposed budget estimates are for the initial set up of the new overarching Environmental Conditions Organization (ECO) and leadership model within a host organization.

	Q3/Q4 2021/22	Fiscal 2022/23
• Annual Operating Cost	$640,000	$2,560,000
• One-time Cost	$290,000	$160,000
• **Total Annual Funding**	**$930,000**	**$2,720,000**

CareNow Ontario's response to the "Laying the Groundwork" report.

Letter to Minister, Sept 2025: Key Request

1. That a senior official within Ministry of Health or Ontario Health be assigned to meet with us to review the findings of this report and to develop a plan to move forward.

2. That the Ministry of Health partner with Environmental Health Clinic and CareNow Ontario to immediately fund a distribution and education strategy for ME/CFS, POTS and FM based on the clinical tools developed by the Centre for Effective Practice.

3. That the Ministry work with CareNow Ontario and other MCS/TILT researchers to establish a process for clinical guidelines and a training and education strategy based on the understanding that MCS/TILT as a biophysical-toxicological condition that is complex, multi-system, recurrent, environmental disorder and a disease process displaying neurological, immunological, cutaneous, allergic, gastrointestinal, rheumatological, cardiological and endocrinological signs and symptoms.

We have not received any response….

- Minister Jones has shown zero interest in doing anything related to this report.
- If the Ministry did respond, is there a risk that MOH will move forward with the understanding that MCS is psychological?
  - The CEP work related to MCS was stopped by the Ministry when the controversy arose with Karen Binkley's article that MCS was psychological. Will Ministry of Health accept the understanding and premise that MCS is biological?
- Can we move forward with work related to ME/CFS, POTS and FM?
- Does MCS need a different strategy?

Open Floor Discussion Thoughts and Questions

Where do we go from here?

Proposed next steps

Next Steps

1. **Dissemination and Evaluation Project for the CEP tools: ME/CFS, FM and POTs**: Kathleen Dennis.

2. **Hospital Accommodation Toolkit for patients with the disability of MCS/TILT**: Varda Burstyn, John Doherty

3. **Clinical Care: OMA Negotiations re K037A**: Dr. Farah Tabassum

CareNow ONTARIO

CARENOW ONTARIO DISSEMINATION STRATEGY FOR CENTRE FOR EFFECTIVE PRACTICE (CEP) ME/CFS, FM AND POTS CLINICAL TOOLS

Kathleen Dennis

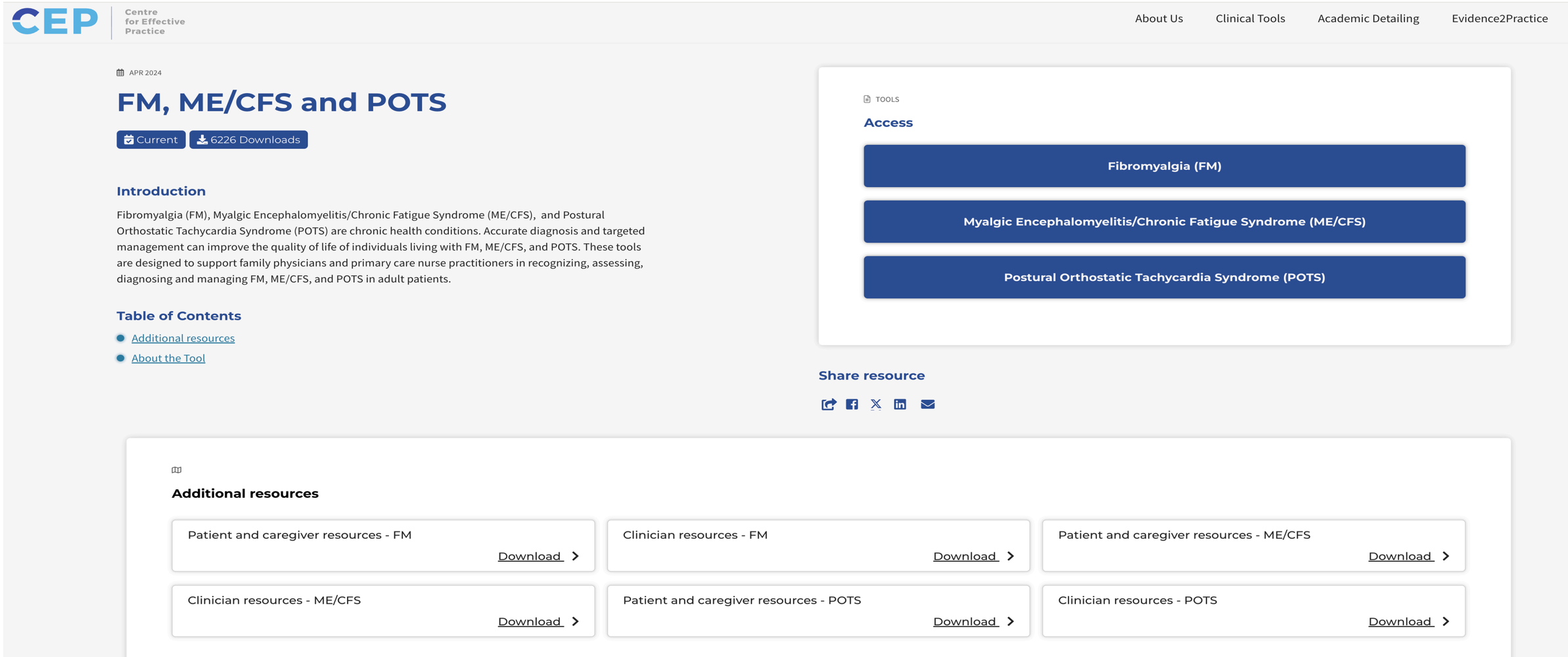
Development of ME/CFS, FM and POTS Primary Care Clinical Tools

- **Early 2023**: the *Centre for Effective Practice* (CEP) was commissioned by the Ontario Ministry of Health to develop post-viral illness primary care clinical tools.
- These tools were part of the **Knowledge Translation in Primary Care Initiative** aimed at supporting evidence-based practice in family medicine.
- **Dr Farah Tabassum** was appointed *Clinical Lead* with a **Topic Expert Group (TEG)** formed, including clinicians, physiotherapists and patient partners,
- The TEG strongly recommended that the illness be **developed as separate but interconnected clinical tools** (not under one umbrella tool).
- **From July 2023 to April 2024,** CEP and the TEG collaboratively developed the content, with additional review from Canadian and U.S. experts.
- The tools were launched on the CEP website in May 2024.

- **NOTE**: The Multiple Chemical Sensitive (MCS) tool was not developed.

CEP Tools Landing Page

https://cep.health/clinical-products/fm-mecfs-pots/



Dissemination and Engagement Gaps….

- The ME/CFS, FM and POTS tools were developed **for primary care physicians and nurse practitioners**

- Although completed, the **CEP did not disseminate** the tools to the Ontario Primary care community (15,000 family physicians and 9,000 nurse practitioners)

Dissemination and Engagement Gaps….

Missed Engagement

- To our knowledge, the **Ontario College of Family Physicians (OCFP)** and the **Nurse Practitioners Association (NPAO**) were not engaged in the tool development – this is a departure from their normal practice.

Implications

- Lack of professional-body involvement reduces awareness, endorsement and confidence among clinicians.

- Limited dissemination risks low uptake and minimal impact in clinical practice.

Strengthening Dissemination and Uptake

Engage Professional Bodies

- Present at the annual Family Medicine Forum
  - 2024 presentation “What every family physician should know about ME/CFS by Dr. Kathleeen Walsh and Dr Daisy Fung
  - 2025 presentation: “Clinical tools for ME/CFS, FM and POTS” by Dr Farah Tabassum and Dr. Kathleen Walsh

- Re-establish collaboration with the **Ontario College of Family Physicians (OCFP)** and the **Nurse Practitioners’ Association of Ontario (NPAO)**

- Seek formal endorsement and integrate tools into their continuing professional development (CPD) programs.

Implement a Dissemination Strategy

- Partner with CareNow Ontario, primary care networks and academic departments to share tools broadly.

- Develop webinars, quick reference guides and e-learning modules for clinical uptake.

Ontario Wide Clinical Tool Dissemination and Evaluation Project

Project Title: Bridging the Gap: Disseminating and Evaluating clinical tools for complex chronic conditions in Ontario Primary Care

Objective: To implement and evaluate the province wide dissemination of clinical tools for ME/CFS, POTS, and Fibromyalgia in Ontario's primary care settings assessing impact on clinician behaviour, patient care and system integration,

Rationale: Despite the development of world-leading tools by the Centre for Effective Practice (CEP), dissemination to Ontario clinicians has not occurred. There is an urgent need to ensure frontline primary care teams are equipped to manage complex, infection- associated chronic conditions.

Ontario Wide Clinical Tool Dissemination and Evaluation Project

Scope and Audience:

- 15,000 family physicians
- 4,000 nurse practitioners
- 184 Family Health Tams (FHTs)
- 75 Community Health Centres

Ontario Wide Clinical Tool Dissemination and Evaluation Project

Approach:

- Dissemination through CME accredited webinars and inservice through:
  - provincial associations (AFHTO, Alliance for Healthier Communities, Ontario College for Family Physicians)
  - Direct facilitations at practice level
  - Presentations at conferences
- Embedded evaluation through RE-AIM and CFIR Frameworks.
- Behavioral change research through clinician surveys, interviews, EMR audits
- Inclusion of patient-partnered knowledge mobilization tools

Ontario Wide Clinical Tool Dissemination and Evaluation Project

Expected Outcomes:

- Increased primary are confidence and capacity in managing ME/CFS, POTS, FM
- Evidence on tool uptake and impact
- Sustainable dissemination infrastructure for future clinical tools

Funding Sources

- Primary Care Branch, Ministry of Health
- CIHR Dissemination and Implementation Science Grant
- Investigate other funding sources

Questions

A TOOLKIT FOR HOSPITAL PREPAREDNESS TO ACCOMMODATE PATIENTS WITH THE DISABILITY OF MCS/ TILT

Developed by Varda Burstyn

MULTIPLE NAMES AND WHY WE CHOSE MCS/TILT

- Most common**: MCS - multiple chemical sensitivity.**
- Ontario and federal governments**: ES - environmental sensitivities**.
- Environmental Health Center, Dallas and American Academy of Environmental Medicine: **EI - Environmental Illness**.
- View of chemical intolerance as psychological in nature: **IEI -** Idiopathic Environmental Intolerance.

WHY WE ARE NOW USING THE TERM MCS/TILT

- Increasing use, much more specific: *TILT, toxicant induced loss of tolerance*.

- Preferred term of an important team of physicians and researchers at the Hoffman Program for Chemical Intolerance at the University of Texas San Antonio Health Sciences Center. They have been doing ground breaking research on (MCS)/TILT for the since the 1990s.

- MCS/TILT is used in the toolkit.

Why CARENOW ONTARIO is initiating a coalition supporting safe care for MCS/TILT in hospitals (1)

- Work with government in 2023-24 finally yielded a real product for ME, FM and POTS: primary care practice guidelines very useful for patients and physicians alike.

- These are multi-page tools, with detailed descriptions of symptoms, with acknowledgement of conditions as medical, physical conditions, with good guidance to physicians about important and necessary diagnostics, treatment and management.

- *But CEP and MoH refused to create a similar tool for MCS.*

Why is CARENOW ONTARIO initiating a coalition supporting safe care for MCS/TILT in hospitals (2)

- Instead, CEP-MoH produced a single paragraph of language that would have set back the cause of recognition and medical response by 40 years.

- Became clear that we needed to seek allies to find ways to bring about essential care directly from health providers as the next step.

- The most urgent of needs among many urgent needs is safer care for MCS/TILT patients in hospitals. Why?

PATIENTS CAN'T AVOID HOSPITALS AT CRUCIAL TIMES …

- If they absolutely must, people with MCS/TILT can avoid workplaces, stores, places of worship, study, recreation.
- But no one can avoid hospitals in emergencies or for critical acute care.
- At the same time…

HOSPITALS WITHOUT AIR QUALITY ACCESIBILITY PROTOCOLS FOR MCS/TILT ARE LIKE HOSPITALS WITHOU RAMPS OR ELEVATORS FOR THE MOBILITY IMPAIRED

HOSPITALS ARE HIGH DANGER ZONES FOR PEOPLE WITH MCS/TILT DUE TO …

- The impact of the negative synergy of chemicals ambient in hospital air (and embedded in materials), especially but not only in high traffic areas.
- This synergy can profoundly exacerbate existing and new symptoms; can threaten success of medical interventions; can set patients back years or permanently; can even threaten life itself.
- The volatile organic compounds from problem chemicals can be measured by scientific devices; show their perception is not subjective; adverse health harms for everyone over time, even those not chemically intolerant.

WHAT ARE THE MAIN CHEMICAL CULPRITS IN THIS NEGATIVE SYNERGY? (1)

- **Hand Sanitizers:** ethanol, isopropanol, or n-propanol (at least 60% alcohol) to kill germs; gelling agents (e.g. polyacrylate), emollients (e.g. glycerin or aloe vera), fragrances, sometimes colorants, sometimes. other antiseptics such as chlorhexidine or hydrogen peroxide.

LITERATURE: MUCH WORSE SINCE COVID.

- **Chlorine bleach:** Chlorinated cleaners can be extremely dangerous to people with MCS, and these are in very common use in many hospitals; have been stopped in many neo-natal, ICU and surgical wards; bad for everyone .

WHAT ARE THE MAIN CHEMICAL CULPRITS IN THIS NEGATIVE SYNERGY?

- **“FRAGRANCES”: these are combinations made up of many other chemicals; i**n perfume and cologne, laundry, cleaning, sanitizing, grooming and medical products. **Contain many different chemicals such as acetone, ethyl acetate, benzaldehyde, formaldehyde (a known carcinogen and major MCS trigger) methylene chloride and phthalates.**

- **FLAME RETARDANTS: Include antimony trioxide, tetrabromobisphenol A (TBBPA), and ammonium polyphosphate (APP**). 4 classes : Brominated, chlorinated, Phosphorus-Based Flame and halogenated. Well established that many of these chemical are associated with adverse health effects on humans and animals.

WHAT ARE THE MAIN CHEMICAL CULPRITS IN THIS NEGATIVE SYNERGY? (3)

- **Solvents and related products**: Metallic and oil-based paints, thinners, certain types of varnishes, adhesives, formaldehyde and so forth. These can be extremely hazardous to MCS patients. It is well known that these types of chemicals even at relatively low concentrations are hazardous to everyone's health; ambient and encountered when the hospital is undergoing renovations or in spaces newly renovated that are still "off-gassing."

- **Emissions from most computer printers**: Most inks still utilize petrochemical materials. The majority still emit microscopic nanoparticles that waft from laser printers. In animal models, have been found to make significant changes in genetic and metabolic profiles in ways that make disease more likely. Such emissions may be found in many places and clearly become part of the ambient atmosphere.

LESSONS LEARNED OVER 25 YEARS OF TRYING

SAFER PATIENT CARE REQUIRES HOSPITAL ACTION THAT CAN'T EASILY BE ORGANIZED ON THE SPOT

- **Individual patients can't win this on their own because the special measures needed are usually received as disruptive when not negotiated in advance. *Emergencies don't allow for pre-negotiation*.**

- **Therefore *policy change establishing hospital preparedness is the key measure required for safer care that must be implemented across the board at the institutional level.***

LESSONS LEARNED OVER 25 YEARS OF TRYING – PREPAREDNESS IS CRITICAL

- Need to bring about the adoption of a clear proposed **PREPAREDNESS PLAN** that helps hospitals be ready for MCS/TILT admission – emergency or elective - such that MCS/TILT patient's admission is not disruptive and so that these patient's disability is accommodated.

- We can't achieve this on our own. We need strong allies and a coalition behind the strategy for change and we need a step-wise strategy for achieving it.

WE HAVE A DRAFT TOOLKIT THAT WE HAVE BEGUN TO SHARE WITH ALLIES

- Our plan addresses the many needs to achieve safer care in hospitals, part of a tool kit with a number of components that together explain and support the needed steps and demonstrate the benefits to hospitals of policy change and plan adoption.

- Varda Burstyn, who has been involved in this struggle since 2009 and is one of the two successful patients to have achieved policy change, has now drafted this 6-component toolkit, and we have begun reaching out to allies, starting with ARCH Disability Law.

The wording on the cover page for the toolkit document says it all:

GREATER SAFETY AND MEANINGFUL ACCESSIBLITY

A TOOLKIT FOR HOSPITAL PREPAREDNESS
TO ACCOMMODATE PATIENTS
WITH THE DISABILITY OF MCS/TILT

THE 3 KEY PRINCIPLES FOR SAFER CARE AND HOSPITAL PREPAREDNESS PRESENT THROUGHOUT THE TOOLKIT

1. **THE DANGERS OF EXPOSURE - what, where, impacts of types of chemicals**

2. **THE PRACTICE OF AVOIDANCE - 2 ways to implement, both necessary**
   - Change the materials used
   - Sequester the patient

3. **THE STRATEGY OF PREPAREDNESS – in 5 action steps**

FIVE ACTION STEPS HOSPITALS WILL NEED TO TAKE TO BE COMPETENT AND ACHIEVE PREPAREDNESS ADDRESSED IN DETAIL IN THE TOOLKIT'S PLAN AND SUPPORTING DOCUMENTATION

1. ADOPT POLICY AND ESTABLISH PROTOCOLS

- Senior management, including clinical management and heads of operational departments, needs to review the proposed plan and the background materials, and devise a customized plan for their hospital.

- A clear triage protocol for the ER is key, as well as identified 'safer rooms' and MCS/TILT stand-by kit.

POLICY IS UP-LOADED AND EASILY ACCESSIBLE TO ALL STAFF; SIGNAGE IS DEVELOPED FOR MCS/TILT STAND-BYE KIT.

FIVE ACTION STEPS HOSPITALS WILL NEED TO TAKE TO BE COMPETENT AND ACHIEVE PREPAREDNESS ADDRESSED IN DETAIL IN THE TOOLKIT'S PLAN AND SUPPORTING DOCUMENTATION

2. IDENTIFY AND KEEP AVAILABLE TWO OR THREE "SAFE" OR "CLEAN" ROOMS TO ENABLE IMMEDIATE SEQUESTRATION

- The hospital identifies two or three possible safe/clean rooms with opening windows and/or negative pressure at meaningful distance from high traffic zones so air quality is better than in those zones.

- Staff is informed of these rooms and can immediately settle patients who come in via ER into them to await further triage and treatment.

This step massively reduces disruption.

FIVE ACTION STEPS HOSPITALS WILL NEED TO TAKE TO BE COMPETENT AND ACHIEVE PREPAREDNESS ADDRESSED IN DETAIL IN THE TOOLKIT'S PLAN AND SUPPORTING DOCUMENTATION

3. ASSEMBLE AND RETAIN STAND-BY MCS KIT WITH NEEDED MATERIALS

- In the proposed plan template the contents for an MCS/ TILT kit of alternative materials, linens, PPE for staff, and other items are specified.

- These can be placed in an impermeable, inert (e.g. *hard* plastic), tightly sealed container and placed on stand-by in a prominent place, to enable easy access for staff to needed materials in the event of an MCS/TILT admission.

- **This step also massively reduces disruption.**

FIVE ACTION STEPS HOSPITALS WILL NEED TO TAKE TO BE COMPETENT AND ACHIEVE PREPAREDNESS ADDRESSED IN DETAIL IN THE TOOLKIT'S PLAN AND SUPPORTING DOCUMENTATION

4. APPOINT LEADERSHIP, ASSIGN ROLES & INVOLVE PATIENT RELATIONS

- Meet with operations department heads to operationalize the plan.
- The hospital assigns **one senior physician** to take responsibility for the policy and its implementation and to be the chief resource person for staff and patients when needs arise.
- **Patient Relations** is thoroughly involved and informed and one staff member from that department is assigned to be the liaison with any and all incoming MCS/TILT patients.

FIVE ACTION STEPS HOSPITALS WILL NEED TO TAKE TO BE COMPETENT AND ACHIEVE PREPAREDNESS ADDRESSED IN DETAIL IN THE TOOLKIT'S PLAN AND SUPPORTING DOCUMENTATION

5. PROVIDE STAFF EDUCATION RE MCS/TILT AND ASSIGN ROLES AND RESPONSIBILITIES OF KEY HOSPITAL STAFF

- Senior management and patient relations seek out department heads - clinical, administrative and support –who participate in preparing and conducting an educational session on MCS/ TILT and on hospital policy for accommodation.

SEVEN COMPONENT DOCUMENTS IN THE TOOLKIT – EACH WITH A PURPOSE

1. Overview and introduction
2. The hospital preparedness plan for MCS/TILT: Two existing examples in Ontario
3. The hospital preparedness plan for MCS/TILT: The proposed templat
4. Understanding chemical pollution, chronic disease and the origins of MCS/TILT – providing an introduction to environmentally linked disease.
5. Understanding and accommodating MCS/TILT as a clinical entity and disability – the nature of MCS/TILT, its requirements, disability policy (environmental and attitudinal barriers), detailed explanation of how to meet these.
6. Selected MCS/TILT bibliography
7. Appendices

Next Steps

1. **ARCH Disability Law** is reviewing the tool kit; revisions will be made before sharing with other potential allies. When this is done …

2. Reach out to **Accessibility Standards Canada** to endorse the toolkit, possibly fund its development.

3. **Reach out to other potential allies** to review and endorse the tool kit after ARCH has completed its review (e.g. CELA, CAPE, women's health organizations, notable physicians including those beyond MCS orbit, EHAC, EHC).

Next Steps

4. Through the **Alliance for Healthier Communities**, conduct a webinar with Alliance leadership and **selected member centres** to request that the Alliance and/or its member centres

   - adopt the plan
   - pro-actively advocate with their hospital partners to adopt and implement the plan as policy, and
   - advocate for their own MCS clients for this accommodation plan when the need arises

Next Steps

5. Post the finished toolkit on CareNow Ontario website so individuals with MCS/TILT can use this tool kit to advocate for their own accommodations. Request EHAC and other partners as appropriate to do the same.

6. Pause and determine next steps given the contours of the health and political environment.

7. Reach out to the Ontario Hospital Association (when the timing is right) to seek support, adoption of policy and plan and opportunities to do education with Hospitals

Questions

PLEASE WRITE TO US WITH YOUR EXPERIENCES IN HOSPITALS

THEY WOULD STRENGTHEN THE TOOLKIT A LOT!

Send stories to:

info@carenowontario.org

Thank You

Clinical Care:

- Focused Practice Designation
- OHIP K037A fee code

Dr Farah Tabassum

Clinical Care: Focused Practice Designation

Focused Practice Designation:

- Reminder update from May 2024:
  - Collaborative efforts from patient organizations (CareNow Ontario, Millions Missing Canada), as well as from Women's College Hospital resulted in all EHC physicians being granted FPD

- Has allowed clinicians to provide virtual care services but there are still limitations:
  - Restrictions in the use of Telephone for appointments
  - Inability to use K037A for initial consult, restricting visit length and structure

Clinical Care: K037A

K037A OHIP Fee Code:

- **<u>Reminder update from May 2024:</u>**
  - New Physician Services Agreement 2022
    - K037A Unchanged - no change to base fee code or addition of premium

- **As of October 2025**
  - New OMA-MOH negotiations underway for next agreement; no voice at the table
  - Ongoing issue of of inability to attract and retain physicians to practice in this field of medicine due to insufficient remuneration structure for complexity of work

Challenges and proposed solutions regarding the K037A OHIP service code for Fibromyalgia and ME/CFS care in Ontario.

Current Issues with K037A

- Established in 2007, K037A is the sole service fee code for ME/CFS and Fibromyalgia care in Ontario, compensating only for direct patient communication.
- Physicians spend significant unpaid time (1-2 hours pre-visit and 2-3 hours post-visit) on chart reviews and report writing, leading to financial strain and volunteerism of about 50% of their clinical time.
- The demand for care has surged post-pandemic, yet the remuneration model deters new physicians from entering this specialized field, and also has resulted in a 75% attrition rate over a 10-year period among trained physicians who completed specialized training in this area of medicine.

Efforts to Address the Issue

- The Ministry of Health (MOH) has stated that OHIP fee concerns need to be addressed by the Ontario Medical Association (OMA), which has not prioritized this issue due to competing interests from other Medical Interest Groups (MIGs).

- The current lack of a sufficient number of practicing physicians prevents the formation of a dedicated MIG, perpetuating the cycle of inadequate representation and support.

Proposed Solutions

- A dedicated OMA leader should collaborate with focused practice physicians to modernize K037A, incorporating a premium for their specialized work.

- The remuneration model must include compensation for both pre- and post-visit activities to ensure fair and equitable payment for the complexity of care provided.

Next Steps

1. CareNow Ontario to advocate with the OMA and the Ministry of Health for the proposed changes to K037

Questions

Thank You to all members and friends of **CareNow Ontario** for participating

If you are not a member – please join CareNow Ontario

WE NEED YOUR VOICE

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