RECOMMENDATIONS FROM THREE ONTARIO TASK FORCES ON CARE AND SUPPORT FOR PEOPLE WITH CHEMICAL SENSITIVITY

Compare and contrast 2017, 2013 and 1985

2017

RECOMMENDATIONS FROM THE INTERIM REPORT
TASK FORCE ON ENVIRONMENTAL HEALTH 2017
Mandate includes ES/MCS, ME/CFS and FM

1. Change the Conversation

Recommendation #1.1 Make a formal public statement recognizing ME/CFS, FM and ES/MCS: The task force recommends the Minister of Health and Long-Term Care make a statement recognizing ME/CFS, FM and ES/MCS. The statement should reinforce the serious debilitating nature of these conditions and dispel the misperception that they are psychological. It should also include a commitment to improve care and education, develop a system of care for people living with ME/CFS, FM and ES/MCS, and provide support for caregivers.

Recommendation #1.2 Establish academic chairs focused on ME/CFS, FM and ES/MCS The task force recommends that the Ministry of Health and Long-Term Care (ministry) fund academic chair positions in clinical environmental health focused specifically on ME/CFS, FM and ES/MCS. The chairs should be located at three different academic health science centres across the province. A key criterion in selecting/awarding these chairs should be a demonstrated commitment to champion improved care for those affected by these conditions.

Recommendation #1.3 Modernize the K037 fee code to include all three conditions The task force recommends that the ministry re-initiate the process to modernize the Ontario Health Insurance program (OHIP) fee code K037 in collaboration with physician and patient experts to ensure it recognizes all three conditions.

2. Develop a Common Understanding of ME/CFS, FM and ES/MCS

Recommendation #2.1 Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care. The task force recommends that the ministry establish an expert panel to reach consensus on clinical

case definitions and clinical practice guidelines for each of the three conditions. The expert panel, which should include people with lived experience as well as input from expert advisors outside Ontario, should meet periodically to review updates in the science on each condition, evaluate the evidence and assess progress in managing the three conditions.

3. Lay the Groundwork for a Person-Centred System of Care

Recommendation #3.1 Establish detailed clinical care pathways to support the development of an evidence-based system of care. The task force recommends that the ministry provide funds to support the development of clinical care pathways for people with ME/CFS, FM and ES/MCS and map out an appropriate patient-centred system of care for Ontario.

Recommendation #3.2 Make hospitals safe for people with ME/CFS, FM and ES/MCS The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure hospitals comply, as quickly as possible, with relevant accessibility and accommodation legislation. As a starting point, the ministry should work with the Ontario Hospitals Association (OHA) to build on relevant prior work, including the Quinte Healthcare Corporation policy on Multiple Chemical Sensitivities and the guidance for hospital staff contained in *Marshall, LM, Maclennan JG. Environmental health in hospital: A practical guide for hospital staff. Part I Pollution prevention, Part II Environment-sensitive care (2001).*

Recommendation #3.3 Make long-term care homes safe for people with ME/CFS, FM and ES/MCS. The task force recommends that the ministry work with its partners and with expert patients, caregivers and physicians to ensure long-term care homes comply, as quickly as possible, with relevant accessibility and accommodation legislation. The MOHLTC should work with long-term care provider associations to build on opportunities within the long-term care home renewal process to improve accessibility and accommodation in existing homes and in the homes of the future.

4. Increase the number of knowledgeable providers

Recommendation #4.1: Continue to fund the Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health. The task force recommends that the ministry continue to fund this program until the task force makes further recommendations for advanced education specializing in ME/CFS, FM and ES/MCS.

2013

ONTARIO CENTRE OF EXCELLENCE IN ENVIRONMENTAL HEALTH NETWORK OF CARE AND BUSINESS CASE PROPOSAL 'IN A NUTSHELL' - 2013

In October 2013, a major, two-year study funded by the Ministry of Health and Long Term Care and the Ontario Trillium Foundation submitted a Business Case and extensive supporting appendices to the MOHLTC outlining a plan of action – '*solutions*' – for a multi-site, multi-function system or network of care, provisionally called the *Ontario Centre of Excellence In Environmental Health (OCEEH).*

All reports and documents relating to this study and its findings and submissions can be found at http://recognitioninclusionandequity.org/ and http://recognitioninclusionandequity.org/resources/

Foundational Steps:

- Ministry of Health and Long Term Care recognize the three conditions as diseases and as disabilities; lead process to change policy in all related ministries and inform educational schools for health providers.
- Ministry of Health and Long Term Care to modernize OHIP codes to include all conditions and make care services insured services
- Ministry to immediately fund expert panel conferences to create case definitions and clinical guidelines.

The hospital- and university-affiliated OCEEH would:

- Develop health provider educational material; assist Minister and medical authorities to mandatorily include it in all educational programs
- Develop the continuum of care from prevention and primary care to highly specialized care and long term care for these groups
- Address the social determinants of health, including shelter and supportive housing – a critical component
- Facilitate a cultural change to acceptance for these conditions as chronic disease and disabilities
- Build or redevelop safe health care facilities where those with ES/MCS can receive care
- Influence social policy to equitably include and address the needs of these groups

- Create and support a leading-edge research and education infrastructure
- Support patients and their families through peer and other support groups and education

Costs will be offset by significant savings thanks to timely access to the right care at the right time.

STRUCTURE AND FUNCTIONS THE OCEEH

TWO PILLARS

- **Pillar One develops a system of care to meet the full range of health and social needs of individuals with these conditions** – people-centered care, integrated, coordinated, comprehensive, and provided by interprofessional teams.

- **Pillar Two works to remove systemic barriers to health equity so that patients and their families can lead full and productive lives**. The goal is to ensure that these conditions are recognized as chronic diseases and disabilities with normal supports throughout government and in medical/health curricula so that they are treated in an equitable manner to other major chronic conditions; and to help government and health care providers understand and improve the impact of many common-use chemicals on human health.

A 'PYRAMID' AND A 'HUB AND SPOKES' NETWORK – 3 LEVELS

- **A specialized 'hub,**' hospital- and university-affiliated, providing diagnosis and treatment for the most complex cases with referral to the hub by any and all physicians; leading a research program; developing education for health professionals, public sector staff, the general public and patients; and policy department to work on barrier removal and general policy alignment. Hub to have air-quality/built environment safe for most serious cases of ES/MCS.

- **6-10 specialized primary care 'spokes'** linked to regional CHCs, directly providing trained primary care and serving as resources for local primary care physicians. Hub to have air-quality/built environment safe for most serious cases of ES/MCS.

- **Linkages with, and education and support for, individual primary health providers** throughout the province, eventually supporting all providers for basic diagnostic and care capacity.

RESULTS OF THE OCCEH

- The patient experience will be transformed – patients will have access to effective, appropriate care and will no longer have to encounter multiple layers of stigma and discrimination
- Serious illness and injury among those who are at the greatest risk of declining health can be prevented and/or and delayed and/or mitigated, with benefits to patients, families, communities and to the province as a whole
- Recent investments in strengthening the primary health care system will be leveraged – the majority of patients will receive care from their primary care provider, who has acquired the required skills and knowledge
- Effective and available social supports, critical to these groups, will be built on and adapted
- A learning environment that can have positive spin-offs for many chronic conditions will be fostered
- Value and sustainability will be delivered through efficient use of resources, including through prevention and appropriate care for patients with environmentally inked conditions.
- Medical and other health provider education will be modernized and state of the art treatment will benefit those with other illnesses as well.

1985

SELECTED RECOMMENDATIONS FROM THE 1985 ONTARIO REPORT OF THE AD HOC COMMITTEE ON ENVIRONMENTAL HYPERSENSITIVITY DISORDERS 1985

Judge G. M. Thomson, J.H. Day M.D., S.E. Evers Ph.D., J.W. Gerrard D.M., D.R. Mcourtie M.D., W.D. Woodward Ph.D. 1985

Recommendation 3: We recommend that research be undertaken to establish the prevalence of environmental hypersensitivity and to determine which of the current tests and treatments being used by clinical ecologists are demonstrably useful.

Recommendation 4: To provide an estimate of the prevalence of environmental hypersensitivity and in the absence of clear diagnostic criteria, we recommend a cross-sectional survey be undertaken using the definition set in chapter two. Because subsequent investigation may prove our definition inadequate, it should be used to identify persons with environmental hypersensitivity for the purposes of this study only.

Such a survey would require the cooperation of those Ontario physicians who are members of the Society for Clinical Ecology and Environmental Medicine.

Recommendation 6: The Committee recommends that the research be carried out in a multi-disciplinary investigative and therapeutic environmental unit, established for a defined period of time, for the assessment of environmental hypersensitivity disorders. We recommend that funding for three years be provided, because this is sufficient for completion of the initial investigations; after three years, it might be reasonable to expect that such an environmental unit would sustain itself through other funding sources, e.g., grants obtained in open competition.

Recommendation 12: The Committee recommends that vitamin and mineral supplements and uncontaminated food and water not be included as insured health services. We do, however, recommend that they be included in health care plans that provide coverage for drugs and other treatments when they have been prescribed by a physician, subject to defined financial limits. Moreover, those who receive social assistance should be eligible for payment through the associated drug or food supplement plans.

Recommendation 17: Both the cost per test and the maximum number of tests per year should be established.

Recommendation 18: That the environmental unit undertake production of easily understood pamphlets on the more controversial issues related to environmental hypersensitivity; that it consider issuing a version of the Committee's report that is easily understood by members of the public; that it ensure adequate involvement in conferences, meetings, etc. sponsored by various advocacy and information bodies recently established in Ontario; that it offer assistance in ensuring that documents prepared by school boards, public health units, etc. are accurate and balanced.

Recommendation 19: In view of the special role that can be played by the public health system, by medical officers of health and, in particular by public health nurses, we recommend that special efforts be made to educate and prepare public health nurses to function as a source of current information on environmental illness in general and on environmental hypersensitivity in particular. These nurses are often the first and most accessible source of information for the patient who is confused by conflicting reports elsewhere. Moreover, this role is consistent with the accent on prevention established in the new Health Protection and Promotion Act.

Recommendation 20: We recommend that programs of continuing education be developed to provide practitioners with the scientific information, which is increasing, that both supports and questions recent, highly publicized theories and beliefs in the field of environmental hypersensitivity. As an example of why this is needed, we note that there is a general lack of understanding of the possibility that indoor are can be a

contributory [sic] factor in illness.

Recommendation 21: All basic social assistance programs, particularly those administered under the Family Benefits Act, should be reviewed to ensure that they recognize how disabled some of these patients are. They should not be deprived of minimal levels of support because of disagreement within the medical profession regarding the causes of their conditions.

Recommendation 22: Because administrators of social assistance programs have wide discretion, the environmental unit should provide expert assistance to appeal bodies such as the Social Assistance Review Board, and to those groups, such as the Community and Social Services Medical Advisory Board, that provide appeal bodies with expert advice.

Recommendation 23: In view of the important role of the individual physician to whom a person seeking social assistance, Worker's Compensation, etc. is referred, those physicians must have current information about environmental hypersensitivity. And must be willing to assess the patient's condition irrespective of any diagnosis attached to it. Here, too, the environmental unit should be involved in selecting such physicians and, in particular cases, should be available to bodies seeking expert advice.

Recommendation 24: Private insurers need to be encouraged to take the same approach in situations where there is a clear disability but some debate as to causation. This is true for those programs that provide payments as replacement for lost income as well as for those that provide assistance for the costs of drugs, extracts and other interventions.

Recommendation 25: At least a portion of the costs associated with special diets and prescribed vitamin and mineral supplements should be claimable through existing food supplement programs and drug plans. Controls would have to be placed on what would otherwise be an extremely open-ended level of support. However, we are satisfied that these measures, when prescribed by a physician after careful investigation and diagnosis, should not be denied those who are simply unable to afford them.

Recommendation 26: In cases of genuine financial need, (i.e., people receiving social assistance) rent supplements or discretionary payments should be available for those seeking to make modest environmental changes.

Recommendation 27: We recommend that the environmental unit collaborate with and assist those involved in the development of special housing programs. Consideration should be given to establishing a nearby apartment, modified for patients who are participants in the environmental unit's research program and are able to reside outside the unit. The unit might also assist some hospitals in making changes to one or two rooms so that patients diagnosed as environmentally hypersensitive would

feel less concerned about being hospitalized when they become seriously ill and required emergency admission.

Recommendation 28: That, in the near future, an interdisciplinary conference be held to discuss this report and its recommendations and that conferences of this type should be held regularly as part of the environmental unit's vital educational role.

Recommendation 29: That the Ontario Medical Association consider establishing an environmental health subsection to bring together practitioners interested in this field.

Recommendation 30: The Committee recommends that the environmental unit develop recommendations for curriculum review committees regarding possible curriculum changes in medical schools to ensure that issue relating to environmental illness are part of medical education.

More in **Recognition, inclusion and equity – The time is now: Perspectives of Ontarians living with ES/MCS, ME/CFS and FM,** Varda Burstyn and MEAO, 2013. Report addressing current state (survey of patients' experience, needs, gaps in services); special analysis of women's, children's, stigmatization issues; in-depth exploration of model of care and delivery; in-depth discussion of issues in barrier removal across government and the public sector. Avaliable at http://recognitioninclusionandequity.org/resources/