

Addressing UnMet Needs

Presented to: Pre-Conference Workshop
Montreal, ME/CFS and Related Illnesses Conference
Facilitated By: Margaret Soden

May 3, 2018

Objectives

- ❑ Receive an Update on the Status of Task Force on Environmental Health's *Interim Report* Recommendations
- ❑ Provide Our Collective Input on the Interim Report's Recommendations' to the Chair of the Task Force on Environmental Health
- ❑ Receive Awareness Education on Diagnosis & Treatment Protocols for ME/CFS & FM
- ❑ Share Our Collective Thinking on Care Pathways

Agenda

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|------|---|---------------------|
| 1:15 | Welcome, Objectives and Agenda | |
| 1:30 | Task Force – Interim Report Update & Input to the Chair of Task Force | Dr. R. Copes |
| 2:30 | Break | |
| 2:45 | Diagnosis & Treatment Protocols | M. Parlor |
| 3:15 | Group Work on Care Pathways | Participants |
| 4:20 | Next Steps for UnMet Needs | M. Soden |
| 4:55 | Meeting Evaluation & Closing Remarks | |
| 5:00 | Workshop End | |

Task Force on Environmental Health

Current Status and Priorities

*Presentation to the Pre-Conference Workshop on
Meeting Unmet Needs*

May 3rd 2018

Presenter

- **Dr. Ray Copes is the Chair of the Task Force on Environmental Health.**
- Currently Chief of Environmental and Occupational Health, PHO
- Received MD and MSc from McGill University
- Completed training in family medicine at Victoria Hospital in London, ON
- Trained in occupational and environmental medicine at St. Michael's Hospital and the University of Toronto.
- Focussed on research, teaching and practice in environmental health
- Appointments: Associate Professor, University of Toronto and Clinical Professor, University of British Columbia
- Other: Medical Director of Environmental Health Services, BC Centre for Disease Control and founding Scientific Director of the National Collaborating Centre for Environmental Health



Task Force on Environmental Health

The task force mandate is to provide advice and recommendations to the Minister of Health for a patient-centred approach to improving supports for people living with environmentally-linked health conditions and on the design of an education and research agenda.

Task Force on Environmental Health

- Conditions include:
 - Environmental Sensitivities/Multiple Chemical Sensitivity (ES/MCS)
 - Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
 - Fibromyalgia (FM)
- Task force includes researchers, patients, caregivers, clinicians, patient advocates, and representatives from other ministries and organizations
- 3 year mandate (2016-2019)

Key messages for today

- The minister acknowledges the serious impact these conditions have on the lives of patients and their caregivers.
- The ministry has been able to take some actions as a result of the interim report of the task force.
- The task force is working toward a final set of recommendations to be provided to the minister before January 2019.

Task Force Phase 1

- Phase 1 (June 2016 to July 2017) focused on developing a shared understanding of the current state of evidence and research on ME/CFS, FM and ES/MCS, as well as the current state of care, health provider education and general awareness about these environmentally linked conditions. Findings included:
 - a lack of recognition of the seriousness and severity of these conditions
 - a profound shortage of knowledgeable care providers
 - a dearth of clinical tools to support and guide care
 - a discouraging shortage of services and supports for people living with these conditions
 - an absence of support for family caregivers.

Task Force Phase 2

- Phase 2 (July 2017 – January 2019) is focussed on developing more detailed recommendations on:
 - the components of a comprehensive patient-centred system of care
 - research required to improve care
 - health care provider and public education required to end the stigma associated with ME/CFS, FM and ES/MCS.

The goal is to enhance quality of care, establish a model of care that will relieve the stresses on people of all ages living with these conditions and on their families, and improve their health and quality of life.

Current status

Interim Report

- Interim report was submitted to the minister in July 2017 [Time for Leadership: Recognizing and Improving Care](#).
- Outlined the current state of research, knowledge, awareness and care regarding the conditions in Ontario, as well as suggested interim steps the ministry could take.
- The interim report was very well received by the ministry, which made it public in September 2017, acknowledging the serious impact these conditions have on the lives of patients and their caregivers.

Interim actions by the ministry

A supportive public statement in the Health Bulletin (September 29, 2017) recognizing the conditions and committing to ongoing efforts to improve care.

An investment of up to \$200,000 for the development of expert consensus on clinical case definitions for ME/CFS, FM and/or ES/MCS that will support clinical care in Ontario.

An extension of the funding for enhanced skills program in clinical environmental health for 3rd year residents in family medicine at the University of Toronto.

Interim Recommendations

1. Change the conversation and increase understanding and recognition of these conditions

- Make a formal public statement recognizing ME/CFS, FM and ES/MCS
- Establish academic chairs focused on ME/CFS, FM and ES/MCS
- Modernize the K037 OHIP fee code to include all three conditions

2. Develop a common understanding of ME/CFS, FM and ES/MCS

- Develop clinical case definitions and clinical practice guidelines to support standardized, high-quality, patient-centred care.

Interim Recommendations

3. Lay the groundwork for a patient-centred system of care

- Establish detailed clinical care pathways to support the development of an evidence-based system of care.
- Make hospitals safe for people with ME/CFS, FM and ES/MCS
- Make long-term care homes safe for people with ME/CFS, FM and ES/MCS.

4. Increase the number of knowledgeable providers

- Continue to fund the Enhanced Skills Program for 3rd Year Residents in Clinical Environmental Health

Current priorities

Final Report

The Task Force's three working groups, Research, Care and Education, have been working hard developing recommendations for their final report to the minister.

Ongoing Inquiries

The task force secretariat has reached out to access additional expertise to support their work when appropriate. For example, it commissioned qualitative interviews of health care providers, and is facilitating work with experts to develop consensus clinical case definitions and research into use and cost of health service for people affected by the conditions.

The task force has received a presentation from Adrianna Tetley, CEO of the Association of Ontario Health Centres about the Ontario Centre of Excellence in Environmental Health business case proposal. The task force continues to use this resource as a reference as it develops recommendations for practical ways to improve access to care.

Commitment

- The task force is dedicated and committed to recommending a patient-centered approach to improving supports, education and a research agenda for people living with environmentally-linked health conditions will lead to practical solutions.
- The experience, expertise and participation of those with lived experience is critical to the ongoing success of this work.

Questions?

Educational Session

Diagnosing and Treating ME/CFS and FM

By: Margaret Parlor, President, National
ME/FM Action Network (Canada)

Diagnosing ME/CFS

- ❑ Oxford definition retired
- ❑ Fukuda definition gone from CDC website

So:

- ❑ CCC – Canadian consensus criteria – describes the illness
- ❑ IOM report – Guides health professionals on how to screen for cases

Diagnosing FM

- ❑ 1990 ACR Definition – widespread pain and tender points
- ❑ 2003 CCC – adopted 1990 ACR but pointed to additional signs and symptoms
- ❑ 2010/11/16 definition – widespread pain + activity reduction + cognitive problems + sleep problems + others
- ❑ US Social Security points to both definitions
- ❑ Many rheumatologists still like tender points

So, **two** diagnostic criteria still in use.

Treating ME/CFS

- ❑ CBT and GET gone from CDC website
- ❑ IACFS/ME Primer – Guide to health professionals on how to treat adults
- ❑ Pediatric Primer – Guide to health professionals on how to treat youth

These are **not** “clinical practice guidelines”.

Treating FM

2012 Canadian Guidelines:

- ☐ Not respectful of possible seriousness
- ☐ Recommends GET without checking for post-exertional malaise
- ☐ Assigns responsibility to family doctors
- ☐ Psycho-social flavour
- ☐ Claims to be evidence based, but most recommendations based on opinion

Treating ME & FM

- ❑ Check for co-morbidities and exclusions
- ❑ Individualize treatment
- ❑ Focus on most troublesome symptoms
- ❑ Pacing, not exceeding limits
- ❑ Patient education

Issues:

- ❑ Lots of discretion when individualizing
- ❑ Pretty standard treatments – focus on good eating, sleeping, etc.
- ❑ Are treatments effective? Rheumatologists don't think so.

Group Work Session

Critical Care Pathways

Care Pathways

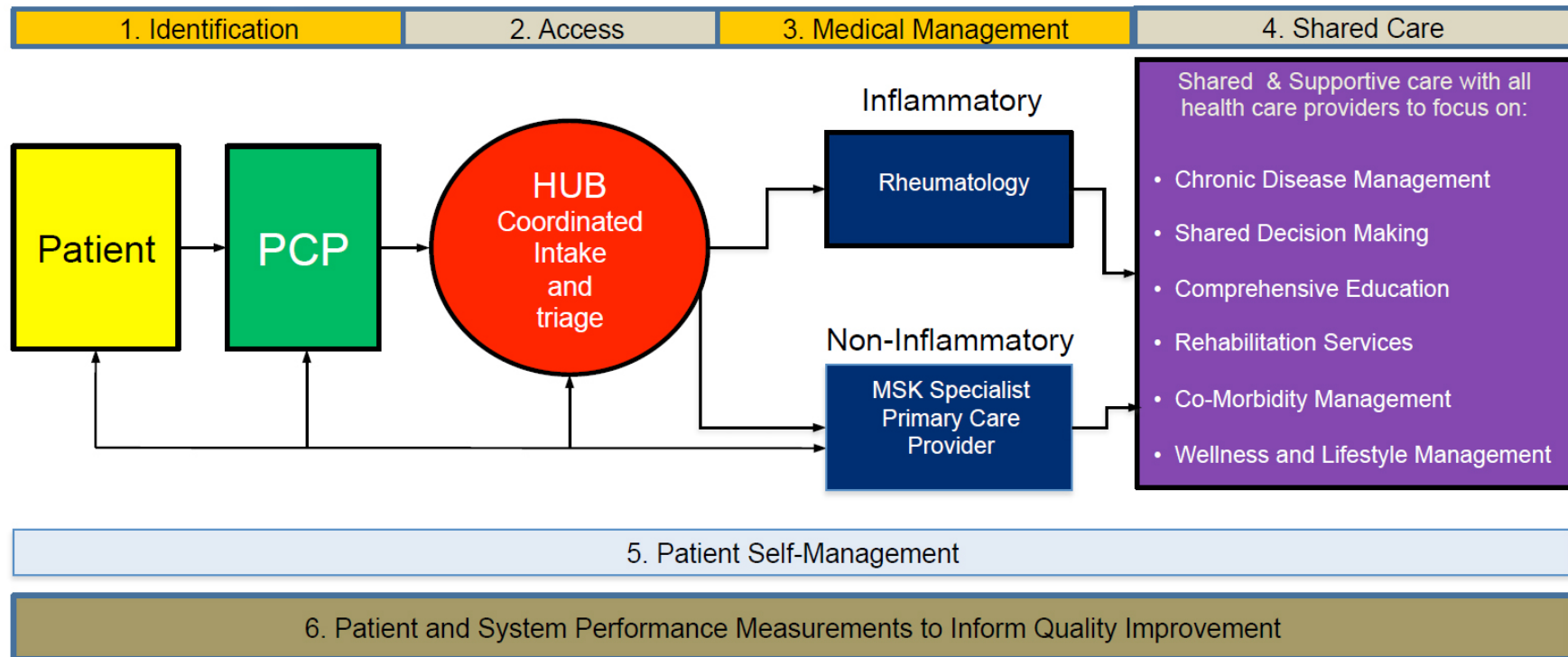
Two examples of care pathways:

- ❑ Inflammatory Arthritis Model of Care
- ❑ CCDP Pathway

Pros and Cons:

- ❑ Family Doctors vs Specialists
- ❑ Centers of Excellence vs Network of Specialists

Inflammatory Arthritis Model of Care



CCDP Pathway



Pros and Cons

Family Doctors

Specialists

+ PROs

Close to home	Concentration of cases
Holistic approach	Leadership in research, training, advocacy
Ongoing relationship	Insurance may allow more flexibility

- CONs

Not familiar with ME/FM	Less accessible
Lack of definitive guidelines	What specialty?
Very busy – short appointments	What can they offer?
	Wait times?

Pros and Cons

Center of Excellence

Network of Specialists

+ PROs

Multi-disciplinary	Spread out geographically
Concentration of specialists	
Allows development of research, education tools, etc.	

- CONs

Patient travel	Not as multi-disciplinary
	Less interaction between professionals

Group Exercise Instructions

Time: 30 minutes

Objective:

- ☐ To come to consensus on recommendations for care pathways

Methodology:

- ☐ Assign a Group discussion leader; a Note Taker/Presenter; and a Timekeeper
- ☐ Allocate your time according to the number of questions (4)
- ☐ Identify the areas of agreement and disagreement in your small group for each question
- ☐ Do you have consensus or not?

Group Exercise Discussion Questions

- ☐ What would a mature care pathway look like?
- ☐ What would work in the short term?
- ☐ Special groups – youth, homebound, rural residents?
- ☐ Who needs to be involved in discussions?

Debrief Group Exercise

Time: 30 minutes total

Objective:

- ☐ To gain input from each group on their views for care pathways.

Methodology:

- ☐ Please let us know if you reached consensus? If so, what is it? If not, why not?
- ☐ *Briefly* share your position on the questions asked.
- ☐ Please provide your flips charts to the facilitator.

Next Steps For Meeting the UnMet

Meeting Evaluation & Closing Remarks

Thank you!



Task Force Recommendations Update

□ Dr. R Copes

1. Change the conversation and increase understanding and recognition of these conditions

- Recommendation #1.1: Make a formal public statement recognizing ME/CFS, FM and ES/MCS.
- 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).
- Recommendation #1.3: Modernize the K037 fee code to include all three conditions.

Task Force Recommendations Update

□ Dr. R Copes

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.

3. Lay the groundwork for a patient-centred system of care

- Recommendation #3.1: Establish detailed clinical care pathways to support the development of an evidence-based system of care.
- Recommendation #3.2: Make hospitals safe for people with ME/CFS, FM and ES/MCS.
- Recommendation #3.3: Make long-term care homes safe for people with ME/CFS, FM and ES/MCS.

Task Force Recommendations Update

□ Dr. R Copes

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.

Further Reading Sources

Task Force on Environmental Health

Phase 1 Report – July 2017:

http://www.health.gov.on.ca/en/common/ministry/publications/reports/environmental_health_2017/task_force_on_environmental_health_report.pdf

Diagnostic Criteria and Case Definitions

CCC (Canadian Consensus Criteria) 2003

Full document: <http://mefmaction.com/images/stories/Medical/ME-CFS-Consensus-Document.pdf>

Short form: <http://mefmaction.com/images/stories/Overviews/ME-Overview.pdf>

International Consensus Criteria: 2011

<http://www.investinme.org/Documents/Guidelines/Myalgic%20Encephalomyelitis%20International%20Consensus%20Primer%20-2012-11-26.pdf>

IOM Report 2015

<http://www.nationalacademies.org/hmd/Reports/2015/ME-CFS.aspx>

Further Reading Sources

Treatment Criteria and Guidelines

IACFS/ME Primer

http://iacfsme.org/portals/0/pdf/Primer_Post_2014_conference.pdf

Bested/Marshall Review:

http://mefmaction.com/images/stories/Medical/ReviewofME-CFS_diagnososandmanagement.pdf

Pediatric Primer:

<https://www.frontiersin.org/articles/10.3389/fped.2017.00121/full>

Other

<http://fmguidelines.ca/>

http://mefmaction.com/images/stories/quest_newsletters/Quest92-Fall2012.pdf

http://mefmaction.com/images/stories/quest_newsletters/Quest104.pdf