

**ME/CFS/FM Pre-Conference Workshop
on Addressing Unmet Needs
Montreal
May 3, 2018**

Feedback from Groups about care pathways

The participants of the pre-conference workshop were split into three groups and given half an hour to discuss care pathways. The groups were asked to record their thoughts on flipcharts. Here are the notes from the three flipcharts.

Group 1

- We recommend the BC CCDP model:
 - Multi/interdisciplinary team
 - Assessment
 - Diagnosis
 - Care
 - Support – contributing
- Short term
 - BC website resources
 - EHC expanded (Ontario)
- Special Groups/Homebound
 - In patient residential
 - Respite for caregivers
- Special Group/Rural
 - Travelling expertise or day program at center
 - Virtual health
- Who is Involved?
 - Doctors
 - Patients
 - Caregivers
 - Social services/other government ministries/agencies
 - LTD
 - Service providers

Group 2

Complex disease Diagnosis

- Specialist clinic
- Admit if needed > PCP gets care plan from clinic
- Education
- Different levels of care >pt education /intervention plan
- Knowledge of specialists >virtual health correction
- Inter professional team >home visits
>research
>medical school education

Needs

- Support –group connection
- Group facilitators – efficiency
- Spoke model
- 1:1 physician appts.
- HIV navigator program
 - Successful program
 - Increase credibility of disease
 - Decrease stigma
 - Community connection and home visits
- Figure out how much is wasted on medical search
 - Unnecessary visits
 - Government needs to know
 - 6 months to 40 year range

Challenges

- True specialist in the field
- Compassion fatigue - health professional burnout with 1.0 FTE

Short Term Must Do

1. Spoke model
2. 1:1 physician appts./information
3. HIV navigator program
 - Successful program
 - Increase credibility of disease
 - Decrease stigma
 - Community connection and home visits

Group 3

Mature Pathway – based on diagnostic criteria

Center of Excellence as the Hub, with ME Specialists (and Medical Student Rotators)

Firstly: TRIAGE with a practical nurse

- Communicate symptoms
- Assessment of symptoms

Secondly: Identify required specialists

The following spokes are attached to the Hub:

- GP that links to the hub
- Techology (Tek/health and business/skype to home) that links outward to the patient from the hub
 - Patient > C.O.E
 - GP/Patient < > C.O.E.
 - This two way approach, reduces costs of missed appointments
- Holistic Approach to care (naturopath; nurse practitioner; counsellor; nurse; acupuncture)
- Appropriate Testing Done By:
 - Internal Medicine
 - Immunologist
 - Dietician
 - GP's
- Social Worker
 - Disability Forms > community support
 - Financial security > issues causing stress
 - Poverty management> documentation assistance
 - Nursing care
 - Home based supports and medical care for severely ill patients
 - Note: severely ill people cannot fill in documents for support from the government as many cannot get to the doctor to fulfill the documentation requirements

What is missing:

- Testing
 - The college MUST allow tests
 - Must not disallow holistic treatments such as saline, vit saline etc.
 - Exclusionary testing !
- Tilt tests
- SPECT scans
- Blood test (extensive)
- Full Panel/inflammatory

Short Term Needs

1. Training and Educating Doctors
2. Diagnostic Criteria and Tests
3. Research Funding
4. House calls/Skype
5. Social Workers for Profoundly ill to help with financial support
6. Employers informed >to allow part time, shared work, work from home - spectrum
7. Change the language to – SPECTRUM
8. Support for caregivers and patients
9. Public awareness campaign....research
10. Anti-stigma campaign
11. Bio Bank

Other Key messages for Dr. Copes:

- There is an urgency for funding for research and for supporting the care/treatments needed by patients
- We need to promote the dangers of G.E.T. /exercise
- We need:
 - National registry
 - Real numbers
 - Real dollars
- We need RESEARCH

Who Needs to be Involved

- Federal Government
- Provincial Government's Health Authorities
- Academia
- Medical Schools
- Medical Associations
- Scientists
- Clinicians
- Nursing Schools/Nurses
- Insurance companies
- Advocates/Patients
- HEC
- Holistic Practitioners: Naturopaths; Physiotherapist