

A primary care physician(PCP) we recently met asked why we don't use their hospital system for treatment of my sons' ME.

I found out that the PCP had never knowingly met ME patients as severely disabled as my sons. And had no clue why we would need to see an ME (Myalgic Encephalomyelitis) specialist.

There is reason to believe this PCP is open to learning. For instance – following our appointments the PCP called the specialist we see for further information. We will endeavour to educate this PCP and hope our input and the specialist's input will spread to others in the hospital system.

I have been thinking about some of the things HealthCare Professionals (HCPs) must know about ME in order to help patients.

Healthcare professionals must:

- Know the differences between definitions for cfs and disease definitions that require post-exertional malaise (PEM) as part of diagnostic criteria.

- Know the range of disease severity and how to assess frequency and severity of symptoms.

- Know that the IOM diagnostic criteria has NOT yet been correlated to any treatment, which means existing treatment guidelines may well be inappropriate (example - those based on Oxford or other definitions).

- Understand that PEM in ME, is *NOT* fatigue. PEM is a systemic exacerbation of symptoms following even minimal cognitive or physical exertion. It lasts anywhere from days to months and is not alleviated by rest.

- Have detailed information about PEM including examples of how it further disables patients (for instance - feeling as though each breath requires conscious effort; inability to make decisions, or use a toothbrush, or roll over, etc.). PEM cannot always be avoided, but careful pacing can help keep it at bay - sometimes. ME forces patients to lead tightly circumscribed lives because minimal cognitive or physical exertion can cause extensive and lengthy repercussions. Getting back to their typical illness baseline is the *best* patients can hope for after PEM.

- Know how to educate patients about pacing. Pacing is *NOT* graded exercise therapy (“GET”). Accurate education about pacing must reflect the nature of energy metabolism impairment and the patient's lowered aerobic threshold.

- Know how orthostatic intolerance manifests and how it compounds disability.

- Understand that cognitive impairment is common and is evident in impaired working memory, slowed processing speed, difficulty with decision-making, slowed speech.... The intelligence is still there but often it seems as though accessing it is almost impossible. HCPs must understand that cognitive impairment is frightening, has dramatic, negative impact on the lives of patients and often necessitates that caregivers/family members must speak for patients because the mere act of getting to the appointment may have already exhausted the patient's cognitive and/or physical resources.

- Treat symptoms (including sleep problems) appropriately to see what else can then be treated – with the goal of improving the patient's level of function/quality of life.

- Know that children get this disease also. Like adult patients, they may be housebound or bedbound. They may be too sick even for homebound tutoring. And HCPs need to know that just because they get it as children doesn't mean they will get better.

Obviously this is more than individual patients/advocates can address to effectively educate HCPs. Like unpieced quilt patches spread widely across a bed, piecemeal education of HCPs by patients/advocates leaves us with a few quilt patches/knowledgeable HCPs scattered across the country and no way to effectively put them together to cover the patients who have no access to the few quilt patches/knowledgeable HCPs available.

And under the current model, as the years go by and the experts retire, more and more patient care will fall to uneducated PCPs and their teams. The reality is that the more patients are undertreated, the greater the rates of disability. This situation cannot continue.

Centers of Excellence for ME staffed by disease experts and providing clinical care are needed to train healthcare professionals that patients alone cannot train. This would greatly enhance the level of care available for patients as well as ensuring appropriate training for HCPs to replace the aging population of currently available specialists.

We urgently need Centers of Excellence for ME to provide more appropriate care for patients, educate much needed healthcare professionals, as well as being a cost saving measure for the overall economy.