A Novel Method of Sharing Practice Patterns: The Mellen Center “APPROACH”

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Abstract

Purpose: To assist other health care providers in treating patient with multiple sclerosis, the Mellen Center clinical team has developed a series of professional “Mellen Center Approaches”. These are basically fact sheets which address a number of issues related to the diagnosis and treatment of MS. The “Mellen Center Approaches” focus on either disease management or treatment. “Approach” can be defined as taking preliminary steps to gaining full knowledge or experience. It is different that a guideline which is thought as a document that arms to describe particular processes according to a set routine. Following the “approach” is never mandatory but a helpful tool for clinicians in providing care for people with MS.

Process: Topics for “Approaches” are determined from suggestions from the clinical team and are prioritized as needed. A clinical group of clinicians is responsible for developing the Q&A for each topic. The document is circulated to all MS clinicians to review and edit the document. The final document is presented at a meeting for feedback. The topics identified in the final documents are formatted in a print format and available online through the Mellen Center website.

Introduction

The Mellen Center (MC) for Multiple Sclerosis Treatment and Research was established in 1995, and is now one of the largest and most comprehensive programs for multiple sclerosis (MS) care and research worldwide. The dedicated team of the Mellen Center focuses on addressing physical, emotional, cognitive, and rehabilitation needs of the MS patient and their family members through a team approach.

The Mellen Center clinical team includes neurologists, physicists, advanced practice clinicians, research nurses, infusion nurses, rehabilitation therapists (physical and occupational therapists) and counselors (health psychology and social work). Mellen Center is national leaders in basic and clinical research related to MS pathogenesis and medical management and has made major contributions in the development of drugs to control MS disease activity and progression. They provide consultation services for neurologists and patients worldwide and ongoing care for approximately 8,000 MS patients annually, including approximately 1,600 new patient/consult visits.

We are dedicated to education at all levels. We provide patient education on a regular basis, schedule regular patient education programs for both newly diagnosed and long term patients. Additionally, we host an annual update in MS in June of each year.

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Format

The format of the MC approaches is Q&A.

An Excerpt From One Approach on Fatigue

Mellen Center Approach: Fatigue in Multiple Sclerosis

Q: What is MS fatigue?
A: Fatigue in the context of MS has been defined as a “subjective lack of physical and/or mental energy that is perceived by the individual or caregiver to interfere with usual and desired activities.” Similar to pain, fatigue is a subjective symptom that can have a profound impact on patients’ quality of life. Fatigue is different from normal exertion in healthy individuals.

Q: How common is fatigue in MS?
A: Fatigue is very frequent in MS (prevalence above 80% in some studies), at any stage of the disease. It is the most frequently reported symptom, and is often cited as the most bothersome symptom by MS patients. Fatigue affects physical and cognitive function, and quality of life. Fatigue has been identified as a source of disability, independent of other neurologic impairments. Work, social, and leisure activities are also impacted by fatigue. Fatigue has been associated with increased health care utilization.

Q: Should any tests be performed in MS patients with fatigue?
A: There is no diagnostic test for primary MS fatigue. At any time in the presence of chronic fatigue, and more particularly in the context of new onset or acute worsening of fatigue, potential treatable causes and contributing factors should be ruled out. For example:

– Current medications should be reviewed, looking for drugs that can cause sedation and could be decreased or stopped, before adding a symptomatic medication for fatigue.
– Depression should be ruled out (we use the Patient Health Questionnaire – 9 (PHQ-9) as a screening tool)
– Labwork should be ordered to rule out acute or chronic comorbidities that can be secondary causes of fatigue (e.g., urinary tract infection, hypothyroidism, anemia, liver or kidney disease, D12 deficiency)
– New MS disease activity should be ruled out through a detailed interview, thorough examination, and if appropriate imaging studies. Fatigue can be the initial symptom of an MS exacerbation, or reflect acute CNS inflammation in the absence of clinical Exacerbation

Q: Is fatigue taken into consideration when MS patients apply for disability?
A: Fatigue can be a reason for applying for disability in MS. This question is discussed in the Mellen Center Approach on disability issues.

Useful resources:

– The MS International Federation recently published an issues of MS in focus on fatigue, which can be downloaded free at http://www.msf.org

Each “Approach” has a disclaimer: this information is not intended to replace the advice of our health care provider. Please consult your health care provider for advice about a specific medical condition.

Future Plans

1) Dissemination of current Approaches. Currently MC approaches can be found on line at www.mellencenter.org, tab For Medical Professionals
2) Continue to identify topics and develop “Approaches” for MS disease management and treatment.