

Understanding and Accommodating Students with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS)

**Ministry of Education
Special Education Policy &
Programs Branch**

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Understanding and Accommodating Students with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia Syndrome (FMS)

- A. Purpose of Presentation**
- B. Introduction**
- C. Symptoms of ME/CFS and FMS**
- D. Educational Implications**
- E. Guidelines for Educators**



A. Purpose

- The purpose of this presentation is to give educators a better understanding of students with ME/CFS or FMS, in order to enhance the educators' ability to accommodate these students in an educational setting.



B. Introduction

- Educators who encounter students with ME/CFS or FMS are often perplexed by the many symptoms, and the degree of disability which they can cause.
- We will describe ME/CFS and FMS, give a summary of the symptoms, and look at some educational implications.



B. Introduction (cont'd)

- What is ME/CFS?
 - ❖ Myalgic Encephalomyelitis (ME)
 - ❖ Chronic Fatigue Syndrome (CFS)
 - ❖ Two terms for an acquired illness that affects all body systems; predominantly the neurological, immune, and endocrine systems
- What is FMS?
 - ❖ Fibromyalgia Syndrome (FMS)
 - ❖ Involves widespread pain of muscles, ligaments, and tendons



B. Introduction (cont'd)

ME/CFS

- Begins with a flu-like illness but persists and then causes deterioration.
- Affects all age groups, racial/ethnic groups, and all socioeconomic strata
- Tends to plateau between six months and six years

FMS

- Triggered by physical trauma, genetics, or comes gradually with no known cause
- Affects all age groups, racial/ethnic groups, and all socioeconomic strata
- Generally does not plateau at a certain age

B. Introduction cont'd

- How do ME/CFS and FMS differ or overlap?
 - ❖ Goals and guidelines for educational planning for FMS students are basically the same as for ME/CFS students
 - ❖ A large overlap of symptoms
 - ❖ FMS incidence rate is higher
 - ❖ Different triggers
 - ❖ ME/CFS – severe fatigue, affects cognitive abilities more
 - ❖ FMS—pain is most prominent feature
 - ❖ Some meet the criteria for both illnesses
 - ❖ Different needs so different emphasis when ***accommodating***

C. Symptoms

ME/CFS

1. Fatigue
2. Post-exertional malaise and/or fatigue
3. Sleep dysfunction
4. Significant Pain
5. Neurological/Cognitive manifestations
6. Autonomic and/or Neuroendocrine issues
7. Immune manifestations

FMS

1. Pain
2. Tender Points
3. Neurological manifestations
4. Neurocognitive dysfunction
5. Fatigue
6. Sleep dysfunction
7. Autonomic and/or Neuroendocrine issues
8. Stiffness

D. Educational Implications

ME/CFS

- There is greater emphasis on accommodating fatigue, post-exertional malaise, and cognitive symptoms

FMS

- There is greater emphasis on accommodating pain symptoms



D. Educational Implications (cont'd)

ME/CFS

1. It is important not to dismiss the illness as lack of motivation, day dreaming or school reluctance
2. Activity boundary limits should not be exceeded
3. Encourage Self-Pacing
4. Rest periods
5. Parents notified as needed (e.g. to pick up their child at the first sign of a migraine)
6. Learning environment
7. Simple instructions
8. Movement issues
9. Frequent bathroom breaks
10. Exposure to substances

FMS

1. It is important not to dismiss the illness as lack of motivation, day dreaming or school reluctance
2. Movement issues
3. Pain is exhausting
4. Never push to the limit
5. Rest periods
6. Parents notified as needed (e.g. to pick up their child at the first sign of a migraine)
7. Learning environment
8. Aware of fatigue types
9. One task at a time
10. Minimize exposure to drafts, cold weather

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D. Educational Implications (cont'd)

ME/CFS

- Some young people may only be able to attend school a few hours a day, while others may be homebound
- Chronic absence from school may exist
- It is important to make available a wide range of educational opportunities

FMS

- It is difficult for these students to complete school work and keep up with classmates
- Chronic absence from school may exist
- They easily become confused and overwhelmed
- Many require special educational considerations

D. Educational Implications (cont'd)

Goals for Educators of Students with ME/CFS or FMS:

- Meet the individual needs of students
- Ensure support and well-being
- Empower and involve students
- Optimize functional ability



E. Guidelines for Educators

Guidelines for Educators of Students with ME/CFS or FMS:

1. Treating physician is responsible for the student's care and should oversee all rehabilitative efforts
2. Respect the biological pathology of the illness and reflect it in educational accommodations (e.g. in relation to the level of daily physical activity and participation in physical education classes)
3. Teachers should meet with the student and parents
4. Individualize educational accommodations
5. Involve students in determining goals, priorities, strategic decisions, and activities



E. Guidelines for Educators (cont'd)

The IPRC Process and Students with ME/CFS or FMS:

- Purpose of the IPRC and IEP processes is to provide needed information to ensure that effective educational programming will be in place for students with ME/CFS or FMS
- Focus is on strengths and areas of need of each individual student through the IEP

Exceptionality: label is not the issue

- Consider Physical Disability: A condition of such severe physical limitation or deficiency as to require special assistance in learning situations to provide the opportunity for educational achievement equivalent to that of pupils without exceptionalities who are of the same age or developmental level.

Placement: Reg. 181/98 requires that IPRC shall, before considering the option of placement in a special education class, consider whether placement in a regular class with appropriate special education services would meet student's needs and would be consistent with parental preference.



E. Guidelines for Educators (cont'd)

Programs & Services for Students with ME/CFS or FMS:

- Consider Education Act: Reg. 298 Sect. 3(3) “A **Board** may reduce the length of the instructional program on each school day to less than five hours a day for an exceptional pupil in a special education program.”
- Consider *Education Act: Reg. 298 Sect. 11(11)* “A **principal, subject to the approval of the appropriate supervisory officer**, may arrange for home instruction to be provided for a pupil where, (a) medical evidence that the pupil cannot attend school is provided to the principal; and (b) the principal is satisfied that home instruction is required.”
- Explore e-learning opportunities to support students.



In conclusion.....

- The publication “TEACH-ME” is a valuable resource for educators that should be available in your school.
- It can be purchased from the National ME/FM Action Network at:
<http://www.mefmaction.net> or The Myalgic Encephalomyelitis Association of Ontario at <http://www.meao-cfs.on.ca>

