

ME/CFS – THE INVISIBLE DISEASE AND ITS EDUCATIONAL IMPLICATIONS FOR YOUNG PEOPLE

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Background

■ An Educator and a Parent -

- *Parent of Twins – My son, Michael, got sick initially in 3rd grade with a mono-like virus, then again in 4th grade and never recovered. My daughter Alexis never got the disease.*
- *Michael was diagnosed initially by our family physician and then by Dr. David Bell, world-renowned Adolescent Pediatrician in ME/CFS.*
- *He never went back to school full time until college, and both he and Alexis just graduated.*
- *Building Principal, Assistant Superintendent, Professor of Education – Specialty in Middle Level Education, Classroom Management and Special Education*
- *My work is in Education and Accommodations and Modifications for Students with ME/CFS.*

What is ME/CFS ?

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

- This Invisible Disease – No known cause, treatment for symptoms, but no cure!
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a disabling, chronic disease characterized by the symptom of insufficient energy to sustain the activities of normal living(1)
- Current estimates are that Americans suffering from this disease range from 1 – 2.5 million, with many of them being children.

What is ME/CFS? – This Invisible Disease – The Parent Perspective

- Your child gets sick with a mono-like virus, gets the flu, doesn't feel good one day and doesn't get out of bed, finishes a soccer meet and is so tired she just goes to bed and never gets up.
- What do you do? You spend months trying to figure out what is wrong with your child – your son or your daughter.
- Physicians often have no idea what is wrong with your child. Many physicians have never heard of ME/CFS; others still erroneously believe it's a psychosomatic or mental health condition.

Course of Illness and Prognosis (1)

- “In a follow-up study of nearly 700 young people the average duration of illness of those who report having **“recovered”** was **4–5 years** with a range from 1 to 15 years. **By 5 years, 60% reported recovery**, and by **12 years, 88% reported recovery**.
- Of those who reported recovery, about one-third admitted to modifying their activities to remain feeling well”
- “Feedback from young people indicated that an important determinant of their functioning as adults was the effort made to enable them to remain **engaged in education.**”

What is ME/CFS?(1)

- “ME/CFS is characterized by **overwhelming fatigue** with a **substantial loss of physical and mental stamina.**”
- Cardinal features are **post-exertional malaise (PEM)** (flu-like exhaustion) and a worsening of symptoms following “*minimal physical or mental activities.*”
- “These post-exertional symptoms can **persist for hours, days, or weeks and are not relieved by rest or sleep.**”
- Symptoms and levels of fatigue **change unpredictably** from day-to-day or week-to-week.

The Invisible Symptoms in Children of ME/CFS (1)

- Post-exertional malaise (PEM) is characterized by the **loss of physical and mental stamina**, substantially reducing the ability to take part in personal, educational, or social activities.
- Sleep Dysfunction—**non-refreshing/disturbed sleep**
- Lack of cognitive focus—**“Brain Fog”**
- Chronic **joint/muscle pains** and aches
- **Headaches** of new onset or severity

The Invisible Symptoms in Children of ME/CFS ⁽¹⁾ (cont.)

- Swollen glands, recurrent sore throat or flu-like symptoms, as well as new sensitivities to food and/or medications
- Neurological/Cognitive Manifestations including confusion; impaired concentration and short-term memory consolidation; disorientation; difficulty with information processing, categorizing and word retrieval; and perceptual and sensory disturbances
- Autonomic Manifestations—orthostatic intolerance (changing from a standing or sitting position results in becoming light-headed and/or passing out); neurally mediated hypotension (NMH); postural orthostatic tachycardia syndrome (POTS)

The Invisible Symptoms in Children of ME/CFS ⁽¹⁾ (cont.)

- **Neuro-endocrine Manifestations:**
 - *Difficulty regulating body temperature*
 - *Developing new allergies or a change in the status of old ones*
 - *Gastrointestinal symptoms such as Irritable-bowel-like symptoms, onset of apparent food allergies - eating former favorite foods causes severe abdominal pain, blood in stool*
 - *Sweating episodes; recurrent feelings of feverishness and cold extremities*
 - *Intolerance of extremes of heat and cold*

Management of the Disease in Children

- Successful management is based on determining the optimum **balance** of rest and activity to help **prevent post-exertional malaise (PEM) worsening**
- **Orthostatic intolerance (OI)** - treated by medications, hydration, increased intake of salt, and teaching patients and those around them to be observant of the symptoms
- **Medications are helpful to treat pain, insomnia, OI and other symptoms.**

What Does Minimal Physical or Mental Exertion Look Like for our Students?

- **Brain Fog** - How do we describe brain fog? You have difficulty thinking, concentrating, forming thoughts. Your students may have known the answers to a simple question yesterday but have no idea what the answer is today.
- **Trying to “push through”** symptoms to complete work or attend school is detrimental to our children. Schools are inclined to push kids, but our kids need to **manage their energy and efforts**. Schools have a tremendous impact in either **validating** the child’s experience with the disease or **trivializing** it. (1)

Attending School

- "While some young patients can attend school, on a full or part-time basis, **many others are wheelchair dependent, housebound, or bedbound.**"(1)
- **How sick is the child?** One minute the child can be sitting in class and the next the child can be in bed and won't be able to get out of bed or the house for weeks or months.

What Do You Do With a Child Who Has ME/CFS in Your School?

- This disease **does not look** the same from child to child, teen to teen, young adult to young adult.
- You can have two students in your school, and they can have very **different** manifestations of the disease.
- This means that every case has to be **individually** assessed, and that you cannot assume that what works with one child will work with the next.

Spectrum of Severity

- “Mildly affected young people might be able to attend school full-time or part-time, but they might have **to limit sports** and after-school activities and have **frequent school absences.**”(1)
- ME/CFS has been found to be **the most common cause of long-term absences** from school (2,3)

“Unrest”—a great resource for nurses and teachers to understand. ...

- Jennifer Brea's Sundance award-winning documentary, **Unrest**, is a personal journey from patient to advocate to storyteller. Jennifer was twenty-eight years old, working on her PhD at Harvard, and months away from marrying the love of her life when a mysterious fever left her bedridden. Her feature documentary won the Sundance 2017 Special Jury Award.
- [Visit the Trailer for "Unrest" here](#)
- [TED Talk—Jennifer Brea](#)

Parents and the school

- For parents of children suffering with ME/CFS, dealing with the school can rival or even replace securing medical treatment as the most **stressful element** of having a child suffering from a chronic illness.
- Parents will spend **more time dealing with teachers** and other school officials than they will in dealing with physicians.
- Parents are **haunted by the fear** that not only will their child **never get better**, but that their child will not receive an education that eventually allows for **employment and independent living**.

When School Becomes a Nightmare

■ Daily Stressors

- *The morning regime – “Are you going to school today?”*
- *“You’re a month behind!”*
- *Communicating with the school – He doesn’t pay attention in class. The teacher doesn’t answer my emails.*

■ Extreme Stressors

- *Officials coming to the house to force a child to go to school*
- *Threatening letters about tardiness or absences to school*
- *Being turned over to social services for neglect*
- *Being drug tested and removed from the school*
- *Classified as having an emotional or psychological disorder*

ME/CFS: What Teachers See

- Families become so familiar with the symptoms of ME/CFS that they don't always realize that teachers see things differently
- Teachers see the child only during the school day (when present), and that child shares the focus with dozens of other children
- Teachers interpret what they see through the lens of the classroom, their experience, and their own expertise (which usually doesn't include ME/CFS and often attributes those symptoms to disinterest, immaturity, ADHD or other problems.)

Seeing and Not Understanding—PEM and Fatigue

■ Post-Exertional Malaise (PEM) and Fatigue

- *1. What Teachers May See:* Child becomes lethargic or falls asleep in class
- *1. What Teachers May Think:* "This child obviously needs an earlier bedtime!"

- *2. What Teachers May See:* Children who miss a large number of classes but look functional when they are present.
- *2. What Teachers May Think:* "This child needs motivation" or "Somebody just needs to make this child get up in the mornings!"

Seeing and Not Understanding—Pain

■ Pain (migratory)

- *What Teachers May See:* Children looking uncomfortable, complaining about nonspecific pain; the school nurse doesn't find any identifiable problem
- *What Teachers May Think:* Hypochondria or other psychological disorder; possibly even symptoms of abuse

Seeing and Not Understanding—Neuro-endocrine Manifestations

- *What Teachers See:* Children complaining about being too hot or too cold to function in a classroom that appears comfortable to everyone else
- *What Teachers May Think:* “These children are trying to avoid working—my classroom is fine! They just want to get out of class to go to the nurse” OR “This is a maturity issue—or maybe this child has ADHD”

Seeing and Not Understanding—Neuro-endocrine Manifestations (cont.)

- **What Teachers See:** Distractibility and confusion
- **What Teachers May Think:** “This child is immature and just needs to learn how to concentrate.”

- **What Teachers See:** Can’t follow readings or answer comprehension questions
- **What Teachers May Think:** “This child isn’t motivated—looks like ADHD to me.”

Seeing and Not Understanding—Neuro-endocrine Manifestations (cont. 2)

- **What Teachers See:** Can't finish tests or assignments on time
- **What Teachers May Think:** “The parents need to get more involved in homework.”

- **What Teachers See:** Repeated dyslexic and/or dyscalculia errors
- **What Teachers May Think:** “This child isn't ready for (or smart enough for) advanced classes.”

Meeting Special Needs of Students Suffering From ME/CFS

- Most educators **do not have a strong** (if any) understanding of ME/CFS, especially as compared to better-known education-related maladies like Autism, ADHD, Dyslexia, or other common psychological disorders
- Many school districts create a “menu” of programs and options for their perceived special needs populations, despite the fact that (in the US) both 504 and Individuals with Disabilities Act (IDEA) don’t work this way; they have strong incentives to fit the student to the program rather than vice versa

Improving Performance: Strategies

- Recognize the reality of the disease:
 - Students *can't "push through"/"self-monitor" fatigue*
 - *Concentration issues result from neurocognitive symptoms, not immaturity*
 - *Irregular attendance; symptom severity varies widely*
 - *Even part-day schedules tax student's energy, leading to "crash"*

Improving Performance: Strategies (cont.)

- Build strategies for the individual student
 - *Emphasize “**Mastery over completion**” in homework and testing*
 - *Grade students on the work produced, not the work they don’t complete*
 - *Year-round schooling supported through homebound instruction is essential*
 - *Long-term plans including a specified route to graduation*

Mastery over Completion—the strategy

■ The Strategy: Mastery Over Completion

- *Define specific skills and content that is absolutely necessary to master*
- *Focus tasks/assignments on mastering these critical skills*
- *Reduce repetitive homework (“Complete problems 1-24”) to **sufficient practice** to **demonstrate mastery** of skill*
- ***Reduce/eliminate** assignments not directly related to **critical** skills*
- *Build on “lessons learned” by the student’s previous classes*

Homebound Instruction—the strategy— for Students with Severe ME/CFS

- **The Strategy: Homebound Instruction**
 - *Tutors who visit the home can allow students to get some work done when it is not possible for them to attend school*
 - *Tutors can administer tests in chunks (over several sessions), so that students do not lose valuable instructional time*
 - *Tutors provide the same focused support for homework and projects, often working during the student’s “best” hours, and can be available on weekends and over the summer*
 - *In many cases, tutors will have to become the primary instructor for at least some classes if not all.*

Rehearsal and Repetition—the strategy

- **The Problem:** Students with ME/CFS don't know where to start an essay or project, and can't seem to get finished on time

- **The Strategy: Rehearsal and Repetition**
 - *Use the same strategies consistently (use ONE prewriting strategy rather than introducing several)*
 - *Provide checklists breaking tasks into essential components, thereby provide a route to completion*
 - *Build additional time to complete sub-tasks into the assignment by shortening assignments or reducing other assignments*

Improving Executive Function

- The Problem: Students with ME/CFS are disorganized and distracted

- The Strategy: Helping the student focus
 - *Treat difficulties as **disease-related**, not behavior problems*
 - *Quieter locations with less noise to complete work*
 - ***Checklists** to be completed today (or within task)*
 - *Structure tasks **sequentially** (don't do one reading in class while requiring a different book at home)*
 - *Check on student at regular intervals (10 minutes), helping to redirect back on task as necessary*
 - *Reduce or limit multi-tasking*

Supporting Processing Speed

- **The Problem: Students with CFS can't work quickly**

- **The Strategy: Structure and “chunking”**
 - *Provide pre-formatted notes to allow students to concentrate on listening*
 - *Permit use of assistive technology (tablets, laptops) to record lectures and keep track of assignments*
 - *Investigate use of microphones/earphones to reduce auditory distractions*
 - *Give prior notice when asking questions, allow extra time to generate and format answers*
 - *Break tasks, assignments, and tests into smaller “chunks” that can be completed in sequence and provide natural stopping places to rest*

What Can Nurses Do?

- School Nurses are the medical professionals who can
 - *Understand and explain* ME/CFS to other educators
 - *Help Teachers locate resources*
 - *Validate* children suffering from ME/CFS and provide a safe, secure place to rest
 - *Help manage medications taken at school*
 - *Communicate with clinicians during the assessment process*
 - *Be an active advocate* for the child as suffering from a real disease in team meetings.

Parents: How to Partner Successfully with the School

- Provide *concrete* information on the illness and potential accommodations, giving staff time to digest the material before instructional plans are made.
- Communicate *frequently* and positively with teachers and staff
- Educate rather than confront; this is a job for a good Parent Advocate who can “translate” between the clinic and the classroom –
- *Parent Information Centers* <http://www.parentcenterhub.org/find-your-center/>
- Take what the school is willing to give you and build on small successes
- “Make your child into a ‘person’” for one teacher/staff member at a time

Laws That Govern Special Needs Students

- Students with mild to moderate cases of ME/CFS could qualify for a **504 Plan**, providing accommodations to their educational environment
- Students with moderate to **severe ME/CFS** could qualify for an Individual Education Plan (IEP), providing both accommodations and modifications to their educational environment.
- Students on an IEP have until they are **21** to get their high school diploma.

Accommodations vs. Modifications: An Important Aside

- These terms are NOT interchangeable
- Accommodations change the learning environment to allow students to meet the same standard or requirements as their peers:
 - *Alternate activities in PE class*
 - *Extended time for tests and/or assignments*
- Modifications are changes made in the learning environment that change the standards or requirements that a student must meet:
 - *Eliminating PE class as a graduation requirement*
 - *Reducing the number or length of tests and/or assignments*

IEPs - Other Health Impaired and 504 Plans

- **“Other Health Impaired”** is the category under which students qualify for an IEP or they may qualify for a 504 Plan
- **504 Plans** come under the Americans with Disabilities Act and allow only for accommodations, but they are put in place more easily
- **IEPs (Individualized Education Plans)** required a full assessment and federally compliant process but provide more options and protections.
- Students with moderate/severe ME/CFS usually qualify for IEPs
- Students on an IEP have until they are 21 to get their high school diploma.

The “Bright Side”—Student Success

- With appropriate accommodations and modifications, even students with moderate to severe ME/CFS can succeed in school.
- Many young people suffering from this disease not only graduate from high school, but go on to successful college careers
- Success begins when we manage to view the disease as the obstacle, not the child suffering from it.

ME/CFS Fact Sheets for Parents and Schools - Accommodations and Modifications in the Classroom

- Contact Dr. Faith Newton at fnewton@desu.edu for a copy of the Fact Sheets.

References

- 1. Rowe, P. C., Underhill, R. A., Friedman, K. J., Gurwitt, A., Medow, M. S., Schwartz, M. S., . . . Rowe, K. S. (2017). Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer. *Frontiers in Pediatrics*, 5. doi:10.3389/fped.2017.00121
- 2. Nijhof SL, Maijer K, Bleijenberg G, Uiterwaal C, Kimpfen JLL, van de Putte EM. Adolescent chronic fatigue syndrome: prevalence, incidence, and morbidity. *Pediatrics* (2011) 127(5):E1169–75. doi:10.1542/peds.2010-1147
- 3. Crawley EM, Emond AM, Sterne JAC. Unidentified chronic fatigue syndrome/myalgic encephalomyelitis (cfs/me) is a major cause of school absence: surveillance outcomes from school-based clinics. *BMJ Open* (2011) 1(2):e000252. doi:10.1136/bmjopen-2011-000252