

Supporting the Pediatric Needs of Educating Students

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CFSAC JUNE 2017

Working Group Members

- u Robin Curtis (CDC),
- u Ken Friedman (Patient Advocate)
- u Alisa Koch (CFSAC member)
- u Beth Matthey (National Association of School Nurses)
- u Carmen Sanchez (US Dept. of Education)
- u Beth Unger (CDC)
- u Vicky Whittemore (NINDS)
- u Special Thanks to Teri Lawler, School Psychologist

Update on January 2017 Recommendations

u Update on January 2017 Recommendations –

- u 1. That CDC coordinate with US DOE Office of Education to disseminate information on Pediatric ME/CFS to all Parent Information Centers.
 - u Progress has been made on designing a landing page on the CDC Pediatric website linked to Parent Information Center Hub (Robin Curtis, Beth Unger, Carmen Sanchez, and Jessica Wilson)
 - u Next steps include developing a webinar around Pediatric ME/CFS that could be used on the Parent Information Center Hub.

Update on January 2017 Recommendations

- u 2. CDC and the School Nurses Association to work together to develop a series of webinars on ME/CFS to be distributed to all school nurses nationwide. (Beth Unger and Beth Matthey)
 - u CDC is finalizing the web content on the pediatric ME/CFS CDC page.
 - u Similar to the Parent Information Centers, the National Association of School Nurses (NASN), would also have a link to the ME/CFS CDC site and the Parent Information Center Hub.
 - u Next steps include work on a webinar that could be utilized by parents and nurses. After the web content is finalized, the funding to support the webinar and whether it is available this fiscal year or next needs to be determined.

Update on January 2017 Recommendations

- u 3. Acknowledging the serious educational implications of pediatric ME/CFS, CFSAC should add one position on the committee's roster for an educator from the US Dept. of Education well-versed in special educational services under IDEA/Section 504 of the Civil Rights Act and the Individuals with Disabilities in Education Act. –
 - u The recommendation has been made for Carmen Sanchez to serve on CFSAC as an ex-officio. We are also waiting for the new members to be appointed to CFSAC. Once the new members are confirmed, there will be a formal recommendation to appoint Ms. Sanchez. Due to a prior commitment, Ms. Sanchez is not able to participate in the June 2017 CFSAC webinar.

Supporting the Pediatric Needs of Educating Students Work Group

- u Suggestions for a two-pronged approach – We have to educate both parents and schools simultaneously about the services and supports students suffering from ME/CFS. What materials are available to support this approach?
 - u Dr. Newton developed ME/CFS Fact Sheets for the Schools.
 - u CDC is working on developing a Fact Sheet – note it has to have “plain language.”
 - u Accommodations and/or modifications that are needed for children with ME/CFS are available on the Parent Information Center Hub website. <http://www.parentcenterhub.org/find-your-center/>

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) School Fact Sheet

SYMPTOMS

- Post-exertional malaise characterized by the loss of both physical and mental stamina
- Sleep Dysfunction- non-refreshing/disturbed sleep
- Lack of cognitive focus (Brain fog)
- Chronic joint/muscle pains and aches
- Headaches of new onset or severity
- Swollen glands, recurrent sore throat, recurrent flu-like symptoms, new sensitivities to food and/or medications
- Neurological/Cognitive Manifestations: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances
- *Neuroendocrine Manifestations:* loss of thermoregulation stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold;
- *Autonomic Manifestations:* orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS).

ABOUT THE ILLNESS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) is a disabling, chronic disease characterized by the body's inability to produce sufficient energy for normal everyday activities. As many as 1 million Americans, many of them children, suffer from this disease.

As an illness diagnosed by exclusion, and with no known cause, there is no single, confirming test. ME/CFS is not a psychological illness, however, though depression and anxiety can occur as it does in other chronic illnesses.

Children with ME/CFS experience debilitating fatigue and malaise (feeling ill) after minimal mental or physical exertion, unexplained by any other underlying medical condition. Symptoms and levels of fatigue change unpredictably from day to day or week to week; all can be exacerbated by stress or exertion; persist for hours, days or weeks; and are not relieved by rest.

Post-exertional malaise is characterized by the loss of physical and mental stamina, substantially reducing the ability to take part in personal, educational, or social activities. Children suffer from lack of cognitive focus and confusion ("brain fog"); non-refreshing or disturbed sleep; light-headedness; and a multitude of painful conditions.

Additional symptoms may include orthostatic intolerance (changing from a standing or sitting position results in becoming light-headed and/or passing out), dizziness, light-headedness and extreme pallor. Students may have difficulty regulating body temperature, and develop intolerance to heat and/or cold; some develop new allergies or have a change in the status of old ones, experience gastrointestinal symptoms, non-refreshing sleep, and pain (myofascial, joint, and/or abdominal) including swollen glands, a sore throat, and headaches.

Neurological and cognitive symptoms ("brain fog") include confusion; difficulty with concentration and processing information; short-term memory deficits; and impaired word retrieval. Many individuals also experience hypersensitivity to light, noise, touch, and/or odors.

There is no single treatment for ME/CFS. Treatment is for symptoms only, and that differs from individual to individual. Many children do not look ill, but they may appear very pale. (ME/CFS in Children and Adolescents, 2017)

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EDUCATIONAL IMPLICATIONS

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) almost always affects the child's attendance in school. Some can attend school daily, some attend part-time, and others are bed-bound. A child appearing fine one day may wake up the next unable to go to school, sometimes for weeks or even months or years. There may be long periods during which the child is incapable of completing any schoolwork. Young, ME/CFS patients will most likely need personalized school schedules to accommodate their medical condition (i.e. homebound services; arriving to school late or leaving early; or only attending school for one or two periods of classes a week).

ME/CFS does not affect intellectual reasoning or language ability. Children should take classes that meet their intellectual needs and, if otherwise qualified, should be encouraged to take Gifted & Talented, Honors, and/or Advanced Placement classes.

Several neurological issues may impact the student's ability to learn. "Brain fog," a state of acute mental confusion or forgetfulness, is one symptom often seen in classrooms. Students also experience difficulty concentrating, have much shorter attention spans, and exhibit slower processing speed. Working memory may also be significantly compromised. Poor physical and cognitive stamina (that cannot be improved) limits the length of time students can spend on activities/tasks.

These issues may manifest in the classroom in several ways. Asked to complete a task and then interrupted, the student may not remember the instructions, or even being asked to do something. The child may take twice as long as healthy peers to answer a question or complete an assignment, and may temporarily lose the ability to retrieve information learned the day before. Increased distractibility from the illness often results in teachers perceiving the student as disinterested, immature, or inattentive. Classroom noises, or even the teacher's voice can be distracting.

These students are particularly at risk for Dyscalculia (inability to handle simple math calculations). They might correctly complete the steps to solve a complex equation, but consistently make simple mathematical mistakes. Dyscalculia should be considered when grading assignments, tests and projects of students with ME/CFS.

RESOURCES

Chronic Fatigue Syndrome in Children and Adults U.S. Centers for Disease Control and Prevention (<https://www.cdc.gov/cfs/pediatric/index.html>)

Parent Information Center
<http://www.parentcenterhub.org/find-your-center/>

Massachusetts CFIDS/ME & FM Association
<https://www.masscfids.org/pediatric>

International Association for CFS/ME (<http://iacfsme.org/Home/tabid/36/Default.aspx>)

Solve ME/CFS
<http://solvecfs.org/mecfs-resources/patient-resources/youth/>

Teach-ME: A sourcebook for Teachers of Young People with ME/CFS and Fibromyalgia
<http://mefmaction.com/images/stories/Support/TEACH-ME2edition.pdf>

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer
<http://journal.frontiersin.org/article/10.3389/fped.2017.00121/full>

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CLASSROOM ACCOMMODATIONS AND INSTRUCTIONAL STRATEGIES

MATERIALS:

- Provide two sets of textbooks – one for school and one for home, online, or eBooks.
- Allow work to be completed and submitted online.
- Teach the student to use an assignment book and online calendar to record assignments and work completed to help with organization
- Allow use of electronic devices in the classroom (e.g. laptop or tablet)

INSTRUCTION

- Review the students 504 Plan or IEP to determine activities that are suitable for the child's medical condition
- Use multi-sensory instruction to focus on child's learning style.
- Address attention/organizational deficits with preferential seating; frequent checks that assignments are recorded and completed; clear directions with frequent feedback, monitoring of on-task behavior
- Teach internal memory aids – including rehearsing information
- Use checklists to break larger tasks down into smaller ones
- Teach tasks serially instead of having the student multi-task
- Support/facilitate social relationships; often the classroom is the only place these students can socialize with other children their own age
- Use visual aids such as graphic organizers and non-linguistic representations

LOGISTICAL/ADMINISTRATIVE

- Examine the daily physical demands: school attendance, distance between classes, number of stairs, availability of an elevator
- Shortened day – Students may need to come in late or leave early. Some students may only be in school partial days two or three times a week or on complete homebound instruction. Procedures to keep accurate track of attendance will need to be put in place
- Flexible scheduling – e.g. the student can attend Tuesday's 8th grade math lesson during any scheduled section of that class.
- Plan a place to rest if fatigue is evident
- Provide tutorial or homebound instruction for work missed or if child is too sick to attend school
- Dietary restrictions may need to be monitored
- Hydration – provide water for the student
- Support and facilitate social relationships within the school when possible.
- Tutoring and Homebound may need to be provided.

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CLASSROOM ACCOMMODATIONS AND INSTRUCTIONAL STRATEGIES

ASSESSMENT

- Work needs to be divided into manageable segments
- Buddy system for notes; teacher outline of material taught
- Alternative ways to test knowledge of material (e.g. providing oral performance instead of written performance or PowerPoint)
- Extra time for assignments, modification of the number of problems and/or assignments completed, no time limit on assignments
- Provide significantly extended time to complete assignments

CURRICULUM

- Focus on mastery of skills rather than completion of assignments
- Essential content needs to be identified/prioritized to shorten the number and length of assignments, projects, quizzes and tests.
- Short frequent projects are preferable to long-term projects
- Tests/Final Exams may need to be given over several days and/or sessions. It may take a student with ME/CFS double the amount of time to complete an assignment or test.

SUGGESTED PSYCHOLOGICAL TESTS AND PROCEDURES

When testing a student with ME/CFS, one must be aware that the fatigue may have an effect or may confound the results of any educational psychological assessments that are administered. Dr. Robert Sedgwick (Bell, et. al, 2005) cautions psychologists and suggests that the student be tested "during their window of opportunity." If the student's symptoms are in the early morning hours, testing the student during that time may yield very different test results than if perhaps you tested the student at 2 p.m. in the afternoon. Testing is not required for a student with ME/CFS but if administered correctly can support the student in obtaining the appropriate school accommodations.

- Wechsler Intelligence Scale for Children ages 6 - 16 (WISC) and the WAIS is used for children 16 and older and adults. Achievement measures academic functioning; it does not measure working memory or processing speed. The digit span subtest measures attention, short-term memory and concentration. The test can be used to indicate whether there is a significant discrepancy between a child's intelligence and their performance at school.
- The WAIS-R can be used to measure the auditory span of attention.
- The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) Form A or B can also be used. To determine if there are deficits in working memory, the psychologist can administer the digit span forward and backwards.
- The Test of Written Language (TOWL) can be used to compare contextual writing, writing an essay and the time comparison and some free thought writing
- Woodcock Reading Mastery Test (WRMT) tests reading skills.
- Computerized Continuous Performance Test (CPT) to evaluate processing speed, simple reaction time and vigilance, and executive function specifically multi-tasking.

Future issues for working group

- u Parents need fact-based documentation about ME/CFS and accommodations/modifications to bring with them to the school.
- u There is widespread inconsistency among States and school districts about the documentation and testing required for an IEP, especially under "Other Health Impaired" (OHI). Best practice recommendations for IEP's need to be created.
- u Parents need to understand the role of intelligence/psychological testing in assessing students suffering from ME/CFS for eligibility for special services.

Critical Issue: Eligibility for Services in Schools for Children with ME/CFS

- u Initial evaluations may require up to 45 working days, so early request for evaluation for special services is critical
- u Schools may not refuse to complete an evaluation as long as the parents complete a request *in writing*. For example:
 - u “We are requesting that our child be evaluated for special services”—language is important
- u Parents should monitor the evaluation process as it occurs

Critical issue: Eligibility for Services in Schools for Children with ME/CFS

- u Data for evaluation may be drawn from:
 - u Parent/teacher interviews/surveys
 - u Attendance records/academic records
 - u Medical records
 - u Psychological testing performed by the school psychologist
- u Psychological testing is not required, but may be useful in documenting issues like short-term memory deficits or slow processing speed, if used correctly.
- u Parents have the right to see all data, testing results and documentation used in decision-making about their child

Critical Issue: Eligibility for Services in Schools for Children with ME/CFS

- u Once the school has gathered and analyzed the documentation, an eligibility meeting is scheduled; parents are included in eligibility meeting
- u The school must provide written documentation of the basis for its recommendation to approve/disapprove special services
- u Being denied for an IEP does not mean the child will be denied for a 504 Plan; standards are different
- u This is the most technical phase of the entire process; a Parent Advocate capable of interpreting test results and understanding IDEA and ADA is highly recommended. Parent advocates can be found at the State's Parent Information Center website.
<http://www.parentcenterhub.org/find-your-center/>

Psychological Testing for Children with ME/CFS

- u There is nothing in the Federal IDEA law that requires that students undergo psychological test for ME/CFS.
- u However, there are several tests that could be beneficial for assessing the student's accommodations.

Recommendations to HHS

June 2017

- u 1. Create Parent-specific Fact Sheets and Fact Sheets for School Personnel on ME/CFS
 - u An ME/CFS Fact Sheet that parallels the School Fact Sheet but is designed in “plain language” with references for parents.
 - u B. An ME/CFS Fact Sheet on the eligibility process for IEP/504 Plans
- u 2. Standardize updates on Pediatric ME/CFS research at each CFSAC meeting.
- u 3. Standardize updates on School Implications of Pediatric ME/CFS annually at the CFSAC meeting