

A Model Physician's letter
(used by permission of parents; all names
changed or identifying data removed)

To whom it may concern:

John XXXX is under my care for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and ? (include other diagnoses such as Postural Orthopedic Tachycardia Syndrome (POTS). After completing a lengthy period of diagnosis (excluding other disorders with overlapping symptoms), John has begun a series of medications meant to target his symptoms causing an improvement, hopefully, in his energy level both physically and mentally. These medications, including (list medications) can cause significant side effects in the beginning and may cause him to miss additional school days. This should be taken into account when developing any educational plan.

With regard to John's functional capability in an educational setting, the following observations should be made: M/CFS involves a complex set of symptoms that can manifest variably in different patients. In John's case, and from the school's perspective, the primary symptoms of ME/CFS that appear will include: (1) extreme fatigue (possibly with joint pain and sleep disorders) that causes him to miss significant numbers of days during the school year, or to arrive at school late or leave early; (2) diminished executive function that will result in increased distractibility, poor organizational skills, and intermittent episodes of "brain fog" during which he will find concentration extremely difficult; and (3) difficulties with processing speed, dysgraphia, and working memory. It is important to note that while executive functions and processing speed are seriously affected, intelligence is generally not compromised by this disease, and with appropriate supports John can be expected to achieve academic success.

The accommodations and modifications recommended below are those that have proven successful with students suffering from ME/CFS:

Specifically, with regard to accommodations and/or modifications in a XXX school, I would recommend: (1) a reduced schedule (half days, late arrival, and/or reduced course load); (2) a hybrid schedule that includes both home instruction and school attendance as he is physically able; (3) exemption from attendance requirements based on the severity of his condition; (4) classroom accommodations to include (but not necessarily limited to): 100% extended time for tests; modified/reduced homework assignments; grading based on the work he manages to complete only; copies of class notes; material presented in sequential fashion rather than multiple topics being covered simultaneously in the same class; an additional set of textbooks for home use; and Extended School Year (or home instruction that continues through the summer months to supplement/support in-class instruction). It is socially and psychologically important for John to attend school as much as possible when his disease permits, even if his completed work lags behind that of his peers.

While the course of this disease is variable with every child, the

accommodations/modifications suggested above have proven effective for many students from ME/CFS in different states.

Sincerely,

XXXXXXXXXXXXXXXX, MD

And how that letter is treated by a school “contract physician”
Reporting to a Child Study Team

This is to inform you that during the last month I have talked to and examined John XXXX, as requested by the district. More than a week ago I contacted Dr. XXXX, who had written a diagnosis letter regarding John two months ago. He promised to get back to me but I have not heard from him as yet.

I feel that unless there are some new, documented medical developments, that John should return to school, although his schedule may be modified if the school believes that will help him keep up.

And what happens when John is referred to a psychiatrist:

John's distractibility and other symptoms present as compelling for ADHD. Symptoms endorsed by the student during the interview include: poor focus; poor sustained focus; easy distractibility; disorganization; forgetfulness; avoidant of tasks. Self-report Short Connors is also suggestive (T score of 86 out of 90). Impairment is moderate to severe. John is developing a "learned helplessness" mentality toward school work that is probably being enabled by his parents' willingness to keep him at home when he reports himself as too tired to attend.

ADHD and CFS likely intersect. It would be reasonable to conclude that symptoms of one disorder exacerbate and worsen the other. Treating John's ADHD would most likely improve (to some extent) his CFS.

Of note, Chronic Fatigue Syndrome (CFS) is typically a diagnosis of exclusion; and remains controversial. Prognosis is quite variable with respect to functioning, and I do not recommend the CFS be included as a primary diagnosis on John's IEP.

DIAGNOSTIC IMPRESSION/FOCUS OF TREATMENT

Axis 1: ADHD—Predominantly Inattentive Typ R/o Unspecified Learning Disorder
Chronic Fatigue Syndrome; School Absenteeism