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## Neurocognitive Problems and the CFS Student

**By Linda Miller Iger**

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Whether you are six or 76, chronic fatigue syndrome (CFS) is a rough illness which requires major lifestyle adaptations. But since school is a mandate for those under 16, young patients of mine have faced special challenges, especially when trying to keep up with their assignments and have a social life. They feel frustrated with not being able to go out, have fun, participate in or watch sports and attend a lot of classes. Perhaps you, too, have had a hard time with your friends who wonder why you are out of school so much. Maybe you've found it difficult to tell them about CFS because of the feeling that there is something wrong with you, or you've not wanted to look sick or be known as having a disease. CFS can have a huge impact on your social life, in particular if you are at an age when you are (or want to be) dating.

You may find that having chronic fatigue syndrome makes attending school and keeping up with assignments difficult. The most challenging classes for young CFS patients are the ones that require in-class participation, such as lab classes where you have to do the work in school. Tests which are timed have been particularly difficult for students with CFS. Despite these challenges, I strongly recommend that you try staying in school if your physical symptoms are not so severe that you are bedridden a large portion of the time. Patients of mine who have stayed in school felt they were better able to maintain contact with their friends than patients who did full-time home study. Certainly the major factor in making a choice between home study and some type of adaptive arrangement with the school is going to be based upon how severe your physical symptoms are. If you cannot get out of bed, there is no way for you to attend school.

Your school needs to know about your CFS diagnosis if your illness causes excessive absences and/or chronic tardiness, or if you require special assistance. Your teachers need to understand that the cyclic nature of the illness may cause uneven performance, especially if you relapse. They should also know about any neuro-cognitive problems you have due to CFS.

As a student with CFS, you may experience any of the following problems: difficulty with bright lights, headaches, visual/spatial distortions, word blocking, word transposition, geographic disorientation or difficulty with calculations or name matching. You may also be easily distracted, unable to maintain attention in a conversation or when reading or only able to concentrate for short periods of time. Short-term memory problems are a primary neurocognitive symptom of CFS. See the box below for an analogy that might help you understand and compensate for deficits you may have.

If you are experiencing these deficits, it is necessary to think about what adaptations need to be made in the school setting to enable you to remain in the classroom. You will need help and support in the school, plus a flexible school setting. When requesting accommodations from your school and teachers, base your recommendations on a worst day scenario, rather than on a best day, which would frustrate both you and your classroom teachers.

Before I propose a list of recommendations, I suggest that you complete the Iger Neurocognitive Assessment on the next page. This assessment can help your teachers and administrators better understand the connections between the impairments you have



and the accommodations that you are requesting.

### **Recommendations for Accommodating Needs of the CFS Student**

1. All teachers that interact with the CFS student should be aware that the student is ill.
2. Due to the cyclic nature of chronic fatigue syndrome, the CFS student's performance in a school setting, where he/she is expected to attend, focus and concentrate, may conflict with the school's attendance or participation requirements. It is suggested that flexible school hours supplemented with tutoring might best meet the needs of the CFS student.
3. Fluorescent lighting may cause problems for the CFS student and if possible, the student should be seated next to a window.
4. Extraneous noises are very distracting to the CFS student. Every effort should be made to sit the student in the front of the class or in a quiet section of the classroom (for example, away from the pencil sharpener).
5. During relapses, the CFS student's speech may become minimal and telegraphic in nature. Telegraphic speech, or highly condensed speech in which only the most essential words, such as nouns and verbs, are used, should not be construed as a lack of effort, insolence or, worst still, stupidity.
6. Teachers tend to call on students who look like they are not paying attention. Because the CFS student is physically ill, it would be better for the teacher to let him/her volunteer to answer questions.
7. The CFS student needs to audiotape all classes. On days when he/she misses a class, providing a tape recording of it would be especially helpful.
8. It is recommended that the student with CFS be allowed to videotape oral presentations ahead of time. Then, if he or she is physically unable to present the oral report on its due date, he or she should be allowed to present the videotaped presentation to the class.
9. The CFS student should receive an extension of time on timed classroom tests and all standardized tests such as CAP, CTBS, PSAT and SAT.
10. The CFS student needs to be notified of projects and/or large assignments a few days ahead of the class so he/she can get these done in time.
11. The CFS student should be allowed to dress as warmly as necessary in the classroom without the teacher(s) calling attention to the CFS student's attire.
12. The CFS student's attention span is greatly limited. Concentration is also compromised. It may be necessary for the CFS student to periodically put his/her head down for a minute or two to refocus attention.
13. The CFS student's posture should not be a source of friction between the student and the teacher.
14. The CFS student may get lost and/or disoriented when changing classrooms. The student should be given more time to get from one class to another. This should not be a source of friction between the CFS student and his/her teachers.
15. The CFS student needs to be excused from regular physical education because exercise is known to make CFS symptoms worse. One adaptive PE program that has worked well for CFS students who can exercise is to be allowed to walk on the track for five, 10 or even 15 minutes, depending on the physician's recommendations and what the student can do on a given day.

Additional accommodations not addressed here may be added based on your individual situation. If you find that even with these accommodations you are unable to function in school or to attend sufficiently to keep up with your assignments, I suggest that you and your parents request an Individual Education Plan (IEP) meeting. At this meeting, you and your parents will have an opportunity to discuss additional accommodations with your teachers and school administrators. If you are unable to attend school regularly enough to keep up with your classes, it might be necessary to have a flexible program where, particularly at the high school level, you would be able to attend your core classes and have home tutoring (either privately or provided by the school) to supplement those classes.

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