

Chronic fatigue syndrome is a frustrating condition that can cause devastation in an individual's life. Due to the disbelief of a concrete physical cause to the condition, often these individuals are never given the full acknowledgement of the devastation they experience, making the condition even more psychologically and emotionally difficult than it already is. Fortunately, chronic fatigue syndrome (CFS) is increasingly being accepted in the medical community as a real, physical illness that can be severely debilitating to those who are affected by it. Despite the increasing knowledge on the subject, the amount of research on how the condition affects children and adolescents is minimal. This is disturbing, considering that this condition, which can cause long-term absence from school, occurs at an age when individuals are psychologically and emotionally most vulnerable. While the Centers for Disease Control and Prevention (CDC) has an adult case definition available, a recently developed pediatric case definition will help to separate management of adult and pediatric cases. This is important because the adverse effects on children's lives can differ significantly from the effects this condition can have on adult lives. The most important difference is that CFS is the largest cause of long-term sickness leading to absence in school. Especially when a child who suffers from CFS only attends school intermittently, the efficacy of the education can be severely lessened (Colby 2006). Therefore, it is increasingly important for physicians to use their medical knowledge on the condition and treatment of CFS to help school systems provide a more thorough and efficient education for children and adolescent patients.

Before 2006, only an adult case definition for CFS existed. General practitioners used the CDC adult case definition to help diagnose CFS but modified it slightly to fit

pediatric cases. “A case of the chronic fatigue syndrome is defined by the presence of the following: 1) clinically evaluated, unexplained, persistent or relapsing chronic fatigue that is of new or definite onset (has not been lifelong); is not the result of ongoing exertion; is not substantially alleviated by rest; and results in substantial reduction in previous levels of occupational, educational, social, or personal activities; and 2) the concurrent occurrence of four or more of the following symptoms, all of which must have persisted or recurred during 6 or more consecutive months of illness and must not have predated the fatigue: self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in previous levels of occupational, educational, social, or personal activities; sore throat; tender cervical or axillary lymph nodes; muscle pain, multijoint pain without joint swelling or redness; headaches of a new type, pattern, or severity; unrefreshing sleep; and postexertional malaise lasting more than 24 hours.”(Fukuda 1994). Exclusionary conditions include any medical condition that may explain chronic fatigue (i.e. untreated hypothyroidism), any previous medical condition that has not been documented as clinically resolved, previous or current diagnosis of a major depressive disorder with psychotic or melancholic features; bipolar affective disorders; schizophrenia of any subtype; delusional disorders of any subtype; dementias of any subtype; anorexia nervosa; or bulimia nervosa, alcohol or substance abuse within 2 years of onset of chronic fatigue, or severe obesity (BMI  $\geq$  45) (Fukuda 1994).

The 1994 CDC case definition significantly improves upon the previous 1988 case definition. However, this definition is more relevant for research purposes rather than clinical practice. Therefore, in 2004, a working clinical definition was developed.

This definition states that a patient with CFS/ME will present with fatigue, post-exertional malaise or fatigue, sleep dysfunction, and pain; have two or more neurological and cognitive manifestations and one or more symptoms from two of the categories of autonomic, neuroendocrine, and immune manifestation; and exhibit illness persisting for at least six months with distinct onset (Carruthers 2004). This clinical definition provides symptoms clusters that provide more specification to aid clinicians.

In 2005, Fowler et al described the adult definition (Fukuda et al 1994) as being too narrow and that a broader definition was necessary for children. Therefore, a much needed pediatric case definition was established in 2006. In children, CFS/ME is defined as clinically evaluated, unexplained, persisting, or relapsing chronic fatigue over the past 3 months. This fatigue must not be a result of ongoing exertion, it is not substantially relieved by rest, it results in a substantial reduction of previous levels of educational, social, and personal activities, and must persist or recur for 3 months. There must also be a concurrence of certain symptoms: post exertion fatigue, unrefreshing sleep, pain that is often widespread and migratory and one or more neurocognitive manifestations. There will also be a concurrence of one symptom from two of the three following categories: autonomic manifestations, neuroendocrine manifestations, and immune manifestations. Exclusionary conditions include medical conditions that explain chronic fatigue and psychiatric conditions that explain the presence of chronic fatigue (Jason et al 2006).

There are some important differences between the adult and pediatric case definitions. First, the adult definition requires that the fatigue be of new onset and not lifelong. The pediatric definition states that only individuals that have reported lifelong chronic fatigue should be excluded, since in children, onset of fatigue may be difficult to

pinpoint and may be insidious in nature. Additionally, due to large amount of developmental changes in children, there may not be a definitive healthy baseline fatigue level. Also, children may not have the cognitive ability to describe fatigue that is debilitating. Therefore, the pediatric definition stipulates that patients only see a reduction in previous activities rather than specifically define the onset of the condition (Jason et al 2006). This also facilitates diagnosis when the child's parents describe the symptoms, as the degree of fatigue is harder to describe by a third party observer than the reduction in activities.

Another difference is that sore throat predating fatigue is not exclusionary in children as it is in adults. Because of the insidious nature of the condition in children, as well as sore throats and such infections being common childhood illnesses, it is not appropriate to exclude chronic fatigue syndrome in the presence of such a condition (Jason et al 2006).

Additionally, the required duration of the fatigue and accompanying symptoms has been changed from 6 months in adults to 3 months in children (Jason et al 2006). This is in response to the recommendation that the definition for CFS was too narrow for children. Studies show that there was no difference between 8-17 year olds with 3 months of chronic fatigue and 6 months of chronic fatigue (Fowler et al 2005).

Another difference is that the pediatric case definition has taken some criteria from the new clinical case definition developed in 2004. The cluster of 4 symptoms required for diagnosis of CFS in children and adolescents is specifically different from the CDC adult case definition of 1994 (Jason et al 2006). This will help increase the definition's relevance to clinical presentations of CFS.

In addition, the clinical case definition of CFS has some ambiguities that are clarified in the new pediatric case definition. The clinical case definition states that fatigue must have “persisted or recurred” for a period of 6 months. The phrase “persisted or recurred” is deemed unclear. Therefore, in the pediatric setting, a seven-point scale is used to determine whether this criterion is met (1 = hardly, 7 = everyday). The symptoms have “persisted or recurred” if the score is at least a 4. Severity of symptoms is also ranked so that inclusion is more standardized (Jason et al 2006).

The last difference between the pediatric and adult case definition is that major depression is not completely exclusionary. Since young children often present with psychomotor agitation, phobia and separation anxiety, and somatic complaints, chronic fatigue syndrome should be considered in the differential diagnosis when the chief complaint is chronic fatigue (Jason et al 2006).

This actually presents specific difficulties and nuances in diagnosing children and adolescents with CFS. Depression is less common in childhood than in adolescence, and it presents differently in the two age groups. While in childhood, as mentioned before, depression often presents with psychomotor agitation, phobia and separation anxiety, and somatic complaints, in adolescence, depression can often present as anhedonia, hypersomnia, weight loss or gain, feelings of hopelessness, and suicide attempts. Because the symptoms of CFS and depression overlap, it is critical for the physician to make a thorough psychiatric evaluation, especially when it comes to children and adolescents. A handy way to distinguish between the two conditions is to evaluate whether the individual has abandoned leisure activities and hobbies altogether, because this is more likely to present in CFS in children and adolescents (Jason et al 2006). However, it is still

increasingly important to determine also whether the individual is depressed because of the existence of CFS, its impact on the individual's daily life, and the lack of acknowledgement of the severity of the condition (Carter 1995). These decisions require special consideration when dealing with children and adolescents.

There are other special considerations when diagnosing children and adolescents with CFS. As with depression, the symptoms of CFS often present differently in children than in adults. For example, fatigue is often not the most alarming symptom that presents (Arav-Boger 1995). The more common symptoms of pediatric CFS include headaches, neuropsychiatric disturbance, dizziness, and myalgia (Carter 1995). Additionally, it is helpful during the diagnosis to realize, especially in adolescents, that patients will often appear to be previously ambitious and athletic, which will present a stark difference in their mentality and activeness after onset of CFS (Jordan 1998). These subtleties in the clinical presentation of CFS in children and adolescents can help a physician make a more efficient diagnosis of CFS.

As one can imagine, the impact of CFS on previously "ambitious and athletic" individuals can have an enormous impact psychologically. This psychological impact can often be even more devastating than the physical impact of the condition. Therefore the first priority of the physician is to approach the patient with sensitivity, understanding, and support (Arav-Boger 1995). Also, when diagnosing CFS, it is important to remember the psychological manifestations of the condition as well. Children will often be psychologically stressed by the condition, so it is important to carefully evaluate a child psychiatrically in order to not confuse CFS with any other psychiatric disorder (Carter 1995). Adolescents may appear anxious and vulnerable (Garralda 2005). It is also

especially important to rule out a somatoform disorder, especially if misdiagnosing CFS in a child will encourage sick behavior (Jordan 1998). Keeping these psychological issues in mind will give physicians a few more tools in helping to diagnose CFS accurately.

The last special consideration when diagnosing children and adolescents with CFS is the difficulty in getting a reliable history. This condition turns out to be equally frustrating to the physician as it is for the patient. Young children are often not cognitively sophisticated enough to recall their premorbid functioning, or to explain their symptoms properly (Jason et al 2006). Therefore, these children may often rely on their parents to describe their symptoms. Parents, unfortunately, may mistake their child's symptoms with laziness, school phobia, malingering or anxiety (Jordan 1998). This can delay an appropriate diagnosis of CFS in children. Therefore, it is necessary for the physician to be aware of the patient-parent relationship during the differential diagnosis (Arav-Boger 1995).

After properly diagnosing a child or adolescent with CFS, it is essential to examine the ways in which the condition affects their life. Specifically, CFS is one of the pediatric conditions that causes the most severe effects on education (Colby 2006). Therefore, it is extremely important to explore what these effects are and how a physician can help to mitigate them. Before illuminating how CFS impacts a child's education, it is critical to understand what the purpose of modern education is. Schooling is a way for children to help develop the ability for logical thought. This includes skills of reasoning and mathematical concepts. Additionally, a social life will develop around the school environment, where children will form relationships with adults outside of their families and with peers of their age. Additionally, they will participate in sports and other

extramural activities (Fadem 2004). It is important for children and adolescents of school age to participate in such activities for normal development.

Children and adolescents that suffer from CFS are often deprived of these emotional, educational, and social opportunities (Garralda 2005). The combination of CFS and the either intermittent attendance or long term absence from school can have devastating effects to a child's development. Children may suffer from reactive and expressive aphasia, difficulties with calculation, problems with attention and wakefulness, and diminished ability for abstract thought, problem solving, and planning (Dowsett 1997). This can severely affect a child's capability to learn the material presented to them. Additionally, problems in gross and fine motor skills, decreased spatial perception, and visual discrimination interfere with practical tasks and independence (Dowsett 1997). This can also affect a child's desire to participate in a sport or extramural activity. Lastly, children and adolescents who experience school absence due to CFS may have reduced socialization with friends, a critical component of the school experience (Garralda 2004). Consequently, CFS can have a major impact of some of the critical components of a child's education.

The large effects of CFS on a child's education can manifest in the child's capacity to emotionally cope with their illness (Garralda 2005). Schooling helps to enhance a child's feeling of self efficacy and helps to reduce feelings of social isolation, which is an issue that is equally important as treating the physical symptoms of CFS. It is the physician's responsibility to assist the school systems in providing a more thorough and efficient education for children and adolescent patients. Some children with CFS may qualify for special services under the Individuals with Disability Education act. Under

Section 504 of this act, no individual with a disability can be denied equal public education participation (Fishbaugh 1992). Students receive an Individualized Education Plan (IEP) if they qualify as “having limited strength, vitality, or alertness due to chronic and acute health problems ...which adversely affect a child’s educational performance” (John and Oleske 2002). A multidisciplinary approach is necessary for an effective IEP to be developed, and this approach absolutely requires a physician’s input.

The one action that the physician has the most control over is diagnosing the illness. CFS is a difficult condition to diagnose, as has been described earlier. It has been shown that a significant minority of general practitioners, to whom CFS in children often presents, have a delay in diagnosing CFS in children (Saidi 2006). This is unacceptable, not only for the obvious reason that delaying diagnosis delays treatment, but that an earlier diagnosis will result in a physician being able to work on improving a child’s education in a more timely manner, before the education is put on hold for too long (Colby 2006). Therefore, it would help a physician gather up the resources for a child with CFS if he or she were able to diagnose the condition sooner. A physician should make every attempt to themselves in educating and preparing themselves in order to achieve this goal.

After a diagnosis has been achieved, the first requirement in the physician’s involvement to provide a better education for CFS patients is to effectively liaison with the school system (Marcovitch 1997). There are a number of options. The physician can choose to request one liaison for the student in the school system who may organize the student’s special services (Garralda 2004). This will provide a unified approach to the child’s special educational needs. Another option for a liaison with the school could be

someone in a position of educational authority (Marcovitch 1997). Often, the special needs of a child with CFS will deviate from the normal practices of the school system. By liaising with an authority figure, it is more likely that changes in education management will occur efficiently. The last liaison that may assist the physician in managing the education of a CFS patient would be the school nurse. A school nurse has the capability of bridging the medical and educational communities, and can be instrumental in helping to create a proper IEP that will be suitable for a student's medical needs (John and Oleske 2002) By choosing a representative at the patient's school carefully, the physician can make the first step in improving the quality of education that a CFS patient receives.

A CFS patient's physician creates and manages the treatment plan in order to see some improvement in the condition. As part of this treatment plan, it is important for the physician to be well-informed on services that may help provide a thorough and efficient education for children and adolescent patients that suits the patient's physical capabilities. With these services, a physician can design a structured, and therefore more successful, educational environment (Colby 2006). One option that a physician can explore is home schooling. There are two schools of thought on this matter (Arzomand 1997). Some believe that home schooling reinforces the behavior or thought that one is incapable of attending school (Marcovitch 1997). Others believe that education at home can lead to better performance than education at school when it comes to CSF patients (Colby 2006). Ultimately, there are a number of factors that must be considered in order for a physician to make an informed decision on whether or not to recommend home tuition. Firstly, the physician must assess whether or not the child's feelings of self worth and success are intertwined with the capability of returning to school (Carter 1995). Often, a child's

absence from school can be devastating, making the child feel unsuccessful and hopeless, which can have significant impact at a time when a child is maturing emotionally.

Secondly, if the treatment plan includes a graded increase in activity, and if the school system is amenable to a flexible schedule, it is possible for the student to return to school initially part-time (Dale 1992). Thirdly, the physician should keep in mind that there should be a balance of energy needed for healing and energy needed for learning. The physician should understand that if the education is interfering with the healing process, the worsening of the disease will lessen the efficiency of the education, therefore beginning a vicious cycle (Colby 2006). Lastly, it is important to consider the social implications of home tuition, and whether by home schooling, a successful integration of peer and extracurricular activities can occur (Wright 1998). If integration of peer activities is not feasible, it may be worth considering some sort of normal schooling if it prevents feelings of social isolation, which can significantly impact a child's social development. By considering all of these factors, a physician can then recommend home tuition or a flexible return to school.

If home schooling is preferred, there are a number of things that the physician can suggest to increase the efficacy of the education provided. It is absolutely necessary that the school system provides the necessary home tutors to provide a quality education despite the limitations of the student. Additionally, the physician should make these home tutors aware of the nature of the student's condition. For example, recommending scheduled naps in the day that may increase the student's performance and requiring graded physical activity to improve the condition (Garralda 2005). Lastly, the physician should perform routine psychological follow-ups with the child (Arav-Boger 1995).

Home schooling may increase feelings of social isolation (Carter 1995). Should such psychological issues arise, the physician can recommend including more peer activities appropriate to the patient's energy level (Dale 1992). That way, the child can have an appropriate network of peers that is not blocked off by their condition. Through these activities, a physician can use medical expertise and treatment plan to increase the efficacy of home tuition.

If a return to school is preferred, the physician can present a number of options to increase the quality of education provided by the school in a manner that matches the student's medical condition. First and foremost, teachers and administrators of the school system must be educated on the nature of CFS (Lim 2002). It is critical that these individuals understand the condition and acknowledge its presence. Often, the most difficult part of living with CFS is having other people understand that it is a real condition that has real impact on an individual's daily life. This is especially difficult for children and adolescents, who must convince many people in a position of authority relative to themselves that the condition is, in fact, not fictional (Gilje 2008). Just this one step can make a tremendous impact on the educational environment for a child with CFS.

There are still many other options a physician can present to a school that will be educating a student with CFS. Firstly, the physician can suggest ways on decreasing the amount of physical activity performed during the school day. This includes access to the school elevator, special transportation to and from school, an extra set of books at home to eliminate carrying books to and from school, and exemption student from physical education (Friedman and Underhill 2007) (John and Oleske 2002). These

recommendations can help reduce the amount of physical activity performed in the day, so that the student's energy does not deplete too quickly.

Due to excessive school absences and possibly only a part-time school schedule, it is necessary that the physician encourage the school systems to be less rigid with certain requirements. The school can allow extra time for exams and assignments, have flexible course requirements, decrease requirements for graduation, and have less rigid attendance policies (John and Oleske 2002). By decreasing rigidities of the school system, students with CFS can be allowed access to a full education at a pace that suits their medical condition. The appropriate pace for the severity of the patient's condition can be determined by the child's physician.

A child suffering from CFS is a serious matter. This child goes from a robust, physical childhood to one where he or she is incapable of doing simple activities like other children their age. He or she might be thought of as being lazy or misbehaved, to those who do not know enough about the condition. He or she may lose self-confidence after parents, teachers, peers, physicians do not fully understand or believe their condition. He or she may lose feelings of self-worth after not being able to attend school like a normal child, or perform at levels that he or she may have been able to previously. All of these feelings, thoughts, issues, are inexcusably preventable. No child, no matter what their disability, should have to feel what these children feel. With a new knowledge on how to spot CFS quickly with a new pediatric case definition, with the tools to help facilitate a more thorough and efficient education, and with the help of their physicians, children and adolescents with CFS can now move into the future more confidently.

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