CFIDS Association of America

working to make CFS widely understood, diagnosable, curable and preventable

The Special Needs of Children With CFIDS

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Living with chronic fatigue and immune dysfunction syndrome (CFIDS) is difficult for all persons with CFIDS (PWCs), as well as their family and friends. However, no group is more severely affected than children who have the disease.

The lessons learned in childhood are those we carry with us throughout life. Knowledge gained from schooling; experience accumulated from interacting with teachers, peers and younger kids; and perceptions of our own abilities--our self-esteem--are some of the many childhood lessons which influence and shape our futures.

Yet children and adolescents with chronic illnesses like CFIDS miss many of these experiences. It is the responsibility of parents, educators, medical personnel and peers to ensure that children with CFIDS enter adulthood furnished with the tools which will give them, like healthy children, a fair opportunity for success and happiness.

In an effort to educate school officials about their role in this process, the Connecticut CFIDS Association cosponsored a one-day workshop for teachers, administrators and school nurses on March 1, 1995. Other sponsors were the Connecticut Department of Public Health and Addiction Services and the Connecticut Department of Education.

This workshop, the first of its kind, resulted from legislation passed in June 1993 which mandated that the state health department educate the community about CFIDS. Although the legislation did not specifically address the need to educate school officials about CFIDS, input from the local adolescent CFIDS support group prompted leaders of the Connecticut CFIDS Association to focus implementation of the legislation on the special educational needs of children with CFIDS.

THE PROBLEM

A Physical Disease

The workshop began with a tutorial on the diagnosis and physical characteristics of CFIDS. David Bell, MD, the nation's leading medical expert on pediatric CFIDS, described the four primary physical symptoms of the disease, which he described as "cohesive" and "specific": fatigue, pain, cognitive deficits and environmental sensitivities.

Level of fatigue can be ascertained by comparing the number of hours a child is active (watching TV, studying, attending school, playing games or sports, etc.) to inactive (sleeping or resting) each day. In healthy children, the ratio of active to inactive is approximately 1:1 (12 hours active, 12 hours inactive). Children with CFIDS spend less than eight hours each day in activity (and none in vigorous activities like sports); severely ill children can only remain active for four hours per day and are unable to attend school.

Pain may include headaches, stomachaches and muscle and joint pain. Dr. Bell has found that the severity of pain often parallels the level of fatigue.

Judging cognitive deficits in children can be very difficult, especially with younger kids. Because they have not had time to determine their true abilities and often have an unclear perspective of "normalcy," children often can't pinpoint extraordinary problems they are having with schoolwork (as opposed to the ordinary problems experienced by their healthy peers). If psychometric or intelligence assessments have been previously made, these tests can be repeated to discern abnormalities (see Cognitive Assessment below).

Environmental sensitivities which develop with CFIDS can include increased problems with light, noise, temperature, odors, drugs and foods and worsening of pre-existing allergies.

Treatment, or "illness management," as Dr. Bell prefers, for the 30 percent of PWCs who are adolescents or children, should include physical, emotional and educational support and symptomatic treatment.

Psychosocial Difficulties

Alan Gurwitt, MD, a Boston psychiatrist who specializes in treating children with CFIDS, stated that the psychiatric problems which plague PWCs are caused by the disease, and not vise versa, as many erroneously believe. CFIDS affects the limbic system and the cerebral cortex in the brain. These organic abnormalities may, in themselves, cause psychiatric problems.

However, the grief PWCs feel as a result of being deprived of formerly enjoyable activities, alienated from friends, stripped of cognitive abilities, unable to plan for the future and forced to cope with the sheer physical pain of CFIDS is not unexpected. All persons with CFIDS mourn the loss of their former lives, but these effects in children with CFIDS can permanently harm life-long self-esteem and self-perception, which are forged during these formative years.

Dr. Gurwitt emphasized children's need to have normalcy in their lives. They need to have "normal" childhood experiences, such as attending school dances, participating in field trips and socializing with friends. He warned that participating in these activities may exacerbate CFIDS symptoms, but asserted that the chance to have normal experiences may, in some cases, be worth the relapse. He advised educators not to punish a child for being ill, rather to create opportunities for the student to participate when he or she is able.

See Dr. Gurwitt's comparison of psychiatric illnesses and CFS.

Cognitive Assessment

Cognitive testing must be conducted by a compassionate clinician who is familiar with CFIDS and/or chronic illness in general, said Robert Sedgwick, EdD. Dr. Sedgwick cautioned educators that fatigue confounds evaluation, thus he recommended that doctors utilize a student's "window of opportunity," the time of day in which he or she feels best, to perform assessment.

The Wechsler Intelligence Scale for Children (WISC)-III can be used to assess a student's cognitive status. No hard patterns have been determined which signal CFIDS. Children with CFIDS frequently have decreases in verbal IQ and attention and concentration, yet performance IQ does not seem to be affected as much. Dr. Sedgwick advised that, in the case where no pre-illness scores are available for comparison, performance IQ may be used to estimate previous abilities on other scales.

In addition, the presence of CFIDS does not exclude a child from having other, pre-existing learning disabilities. If a child has been diagnosed with an attention deficit, language or other disorder, this must be addressed in addition to the problems caused by CFIDS.

See Dr. Sedgwick's list of tests that may be useful in establishing a CFIDS student's educational needs.

THE EXAMPLES

Although the morning session, which provided workshop attendees with the nuts and bolts of the disorder, was essential, true understanding was established by a mid-day session which gave those living with CFIDS an opportunity to describe their experiences. Six adolescents with CFIDS and the mother of two of these children spoke for 45 minutes about how it really feels to have CFIDS.

The kids related the problems of trying to keep up with schoolwork and attempting to maintain social relationships even though they are too ill to attend school; combating the disbelief of teachers and students (fighting the "but you don't look sick" reactions); trying to fit in with their peers; and dealing with the unpredictability of their health and the havoc it wreaks on their cognitive abilities.

The mother of two boys who became acutely ill with CFIDS four years ago, described the lengths to which she and her husband have gone to minimize their sons' losses and continue their education. In the first 18 months of their illness, she and her husband had to read their sons' textbooks aloud to them. But, since each boy was only able to concentrate for a short period of time, they would read to one for 10 minutes and then allow him to rest while they read to the other for 10 minutes, going back and forth between the boys. Since one child was unable to walk the long halls of his high school without experiencing mind-numbing fatigue, she would meet him after each class and drive him to the doorway nearest the next classroom.

Miraculously, all of the children on the panel continue to keep up with their schoolwork and most are getting excellent grades. One, a high school senior, will graduate this spring, likely as valedictorian of his class, and has been accepted to his first-choice university. Nicole, a 16-year-old, continues to make the honor roll even though she is too ill to attend school and depends upon a tutor.

An audience member commented that the adolescents on this panel all have chosen to expend their limited energy on schoolwork over social activities. When asked why this decision was made, Todd Dyer, a 17-year-old, said "education is the most important thing. You have to hope that you're going to get better and in five years, if you just tried to socialize with your friends and you're not finished with high school, how much fun is that going to be?"

THE SOLUTIONS

The afternoon session focused on ways the school system can make accommodations to educate students with CFIDS. The Education of the Handicapped Act (Public Law 94-142) was enacted in 1975 and amended in 1986 (PL 99-457) "to ensure that all children with disabilities would have a free, appropriate public education which would meet their individual needs."(1) In 1990, the law was again amended and its name changed to the Individuals with Disabilities Education Act (IDEA).

Elaine Brainerd, RN, MA, CSN stated that children with CFIDS may qualify for special services under IDEA or Section 504 of the Americans With Disabilities Act (ADA).

IDEA provides additional federal funding to schools for educating students with one or more of 13 listed conditions. PWCs may qualify under other health impaired: "having limited strength, vitality or alertness due to chronic or acute health problems which adversely affect a child's educational performance." Students who are eligible receive an Individualized Education Plan (IEP) written by a multidisciplinary IEP team.

Section 504 protects the rights of handicapped/disabled children to a free and appropriate education, including special accommodations as needed. To be eligible for the program, students must have an impairment which substantially limits one or more major life activities. Many conditions not covered under IDEA will qualify for Section 504 protection. No additional funding is awarded to schools educating children under Section

504, which is essentially a very broad piece of civil rights legislation. Like IDEA, Section 504 requires that an educational plan be created for each eligible student.

Dr. Robert Sedgwick reported that, when faced with an unknown problem (like CFIDS), schools often rely upon a "moral" model of intervention, which assumes that human willpower is strong enough to prevent and overcome problems (this is the "just say no" model). Unfortunately, this often unwittingly places blame on a student who is unable to compensate for a disabling condition.

Both Ms. Brainerd and Dr. Sedgwick commented on the difficulty the traditional school system has in accommodating the needs of students with CFIDS. Solutions to these problems include treating students as individuals, setting less rigid attendance policies, allowing extra time for tests and assignments, permitting make-up work, involving the student in scheduling, providing the student with a syllabus or schedule of upcoming assignments so he or she can keep up with the class when unable to attend school, etc.

Richard P. Prunty, EdM, CAGS is a high school guidance counselor who helped create and implement an IEP for a girl with CFIDS. Some of the accommodations made for this student included: providing van transportation to school and access to the school's elevator; setting flexible class schedules and assignment deadlines; furnishing a tutor and an extra set of textbooks for her home; and allowing her to graduate without taking physical education.

Because of her reduced class schedule, this student may not graduate from high school in the traditional four years, said Mr. Prunty, but she will get complete access to the educational system and will be well-prepared for her future.

This workshop was extremely successful in educating over 150 educators and school nurses about the special needs of children with CFIDS. As one workshop attendee commented, educators know what to do to make accommodations for students with CFIDS because they do it every day for children with asthma and other chronic illnesses. What educators need is to learn about CFIDS.

References

1. Pamphlet: Disabilities which qualify children and youth for special education services under the Individuals with Disabilities Education Act (IDEA). Produced by the National Information Center for Children and Youth With Disabilities (NICHCY). For more information, write PO Box 1492, Washington DC 20013-1492; or call 800/695-0285.

An act concerning chronic fatigue and immune dysfunction syndrome June 28, 1993

Be it enacted by the (Connecticut) Senate and House of Representatives in General Assembly convened:

The commissioner of health services shall implement, using existing resources, state-wide informational outreach programs on chronic fatigue and immune dysfunction syndrome. The programs shall include medical and patient education programs and public awareness campaigns.