WHY CHILDREN WITH CFS ARE OFTEN OVERLOOKED

by Frank Albrecht, Ph.D. and Rebecca C. Moore April, 1996

Chronic Fatigue Syndrome is overlooked or misdiagnosed in children even more often than in adults. Everyone is at fault -- parents, doctors, counselors, nurses, even the kids themselves.

Suppose yourself a reasonably well-informed mother enjoying normal good health. Your 14 year-old daughter says to you: "Mom, I'm awful tired all the time. And my bones hurt, or something. And I feel like I can't think straight anymore. I feel weird."

What might you think?

Adolescent adjustment problems?
Late nights, too many activities?
Menstrual problems?
Lack of vitamins and minerals?
Growing pains?
Depression?
Avoiding school or work or other responsibilities?
Lovelorn?
Sexually active?
Drug or alcohol use?
Hypochondria?
Mononucleosis?
Lyme Disease?
Just plain fussiness?
Chronic Fatigue Syndrome?

Most likely you'd consider "all of the above" as being possibilities -- EXCEPT Chronic Fatigue Syndrome!

Professionals do the same.

A couple of years ago a mother brought her "depressed" 13 year old to co-author Frank Albrecht for treatment. This girl had poor grades and terrible school attendance. At home, her mother said, she was "moody," "lethargic," "inactive", "weak", a "night owl" who fell asleep late and was often very tired in the morning. She complained constantly of aches, pains, and sore throats for which the doctor could find no cause. She rarely did any thing with her friends, spent much of her time doing "nothing" in her room, and often refused to participate in family activities and outings.

The girl agreed that she was depressed. But she said also that nobody tried to understand how tired she was after a day in school, that her sore throats often came with a painful stiffness in her back, that her joints hurt even if the doctor thought they shouldn't, and that family activities wore her out so much she couldn't enjoy them.

This picture screams Chronic Fatigue Syndrome! But Albrecht had no personal experiences of this illness, so he bought into the idea that this was an atypical depression, or perhaps an adjustment disorder.

It's that easy to overlook pediatric CFS! Albrecht's mistake is repeated daily by physicians, nurses, counselors, parents, and friends of young people who have CFS.

These kids are often seen as unintelligent, lazy, shy, socially awkward, uncooperative, or unmotivated. As their illness progresses, teachers and parents may dismiss them as naturally moody, maladjusted, misbehaving, or slow-learning -- having forgotten that in prior years they were very different.

Pediatric CFS is particularly frustrating to physicians because the kids' complaints tend not to be consistent. One month it's sore throat, headache, and dizziness that are most disabling. The next month three other symptoms are the most significant. Somatic complaints are in fact common among upset children, so it's easy for doctors to see these shifting symptoms as a cover up for underlying emotional or school problems.

Three objective factors also lead physicians away from recognizing CFS:

1. Most pediatric training programs do not include CFS. Traditional training, in fact, is that any complex or confusing presentation of symptoms that include pain means emotional problems. Physicians who treat children are biased by this training against recognizing CFS in their patients.

2. CFS in children often has gradual onset. This means that by the time the disease is serious the low energy levels, poor school performance, aches and pains, and other symptoms may be seen as "normal" for that child. The physician may not know the child has ever been different. Or, the change may be seen but rationalized as "going through a phase," "growing pains," or just "adolescence"!

3. CFS has a different presentation in children than in adults, so kids may get several years into their illness before they present the "right" symptoms for meeting formal criteria for CFS. The variation in symptoms and in symptom intensity, combined with the relapsing/remitting course of the illness, may not be consistent with what most pediatricians think CFS is.

The kids themselves often decide that their symptoms are too normal to mention, or so strange they should be hidden. Co-author Rebecca Moore, for instance, assumed her friends had the same kind of fatigue she did, but that they handled it better. She had other symptoms -- such as losing her way in familiar hallways -- she wouldn't mention to anyone because they seemed too "weird." Children and teens often feel guilty for noticing their symptoms, or even for having them! So they say nothing, leaving their parents to suspect something is wrong, but depriving them of any way to find out.

Adults, including physicians, often don't take children's complaints very seriously. Children, for their part, do not have the kind of autonomy and assertiveness that it takes to stand up to adults who do not believe them. It's hard enough for adults to do that with each other!

Saying unpopular things takes guts, plus confidence that one's complaints are valid. If respected adults (parents, grand parents, teachers, doctors) all say that a child is lazy, or uninterested, or exaggerating his problems, few children can calmly reply, "You don't understand. Let me explain this."

Most children, in fact, believe that what adults tell them must be true. If they are told they are not sick, they believe it.

Children whose CFS started gradually get used to the way they are, and may insist they are not sick even if a doctor tells them they are! If a child like this becomes increasingly ill, she may recognize in retrospect that her problems were caused by illness -- yet still in her heart think of herself as having been shy or unintelligent.

Children tend to see their symptoms as being signs of poor social skills. At ages 12 or 13, one is both self-absorbed and interested in relating to one's peers. Being different isn't acceptable. If friends don't appear to have the same fatigue or pain, then they must either be covering it very well, or not have the symptoms at all. Either way, they are "better" or "more cool" than someone who shows herself as sick.

Another problem is that a lot of kids with CFS have one or more parents or relatives with a similar illness. This makes what's wrong with them seem normal. For instance, one symptom of neurally medicated hypotension is needing to lie down and rest after a hot shower. Dr. Peter Rowe relates that in the family of one of his patients every female for generations has had to lie down after a shower! They all had the illness so none of them thought this behavior was odd.

Once a wrong diagnosis gets fixed, it's hard to change. Many CFS kids, for instance, are diagnosed with school phobia or school avoidance. Others, like Frank Albrecht's client, are treated for depression, or for other emotional/behavioral disorders. If the illness gets worse, it's simply assumed that the child is resisting the treatment, won't really engage with her counseling, and so forth.

Another factor is social class and social self-confidence. Dr. David Bell points out that it may take a lot of assertiveness for even an adult to obtain a diagnosis of CFS. The first doctor you see about this disorder typically says it's all in the mind, it's an exaggeration of normal feelings, or it will go away in time. If the patient persists in returning to the doctor to say that something is wrong, the physician often becomes irritable and dismissive. To persist in the face of such rejection is difficult! Those who do it are usually above average in intelligence, income, and self-confidence.

Uneducated and poor people rarely are able to stand up to a doctor or ask for another opinion. They are intimidated by the doctor's knowledge and social prestige. They are unsure of their perceptions, and feel guilty when the doctor is annoyed with them.

Even when they feel strongly that the doctor is wrong, they typically say and do nothing about it -- because they don't know how. It takes not only self-confidence, but an unusual degree of social skill to deal with skeptical professionals and uncooperative insurance companies.

Children are usually taught to respect physicians and not to disagree with them. Many are afraid of doctors. Children with CFS are often told by their pediatricians, in a kindly and advice-giving way, that there is nothing much wrong with them, or they are exaggerating, or they should try harder, or they are trying to avoid their responsibilities. These children usually feel that they cannot tell the doctor that they disagree with him: they fear he will be annoyed and not like them anymore -- and not want to help them anymore. Such children often try to get well through a mystical feat of the mind. And they often lie to the doctor, telling him what he wants to hear in order to avoid his disapproval.

In summary, CFS in children is often overlooked because:

1. Parents aren't familiar with it or looking for it in their children.
2. The early symptoms often lead to an incorrect diagnosis of emotional or adjustment problems, which forecloses looking further for explanations.
3. Children often misinterpret their symptoms, seeing them as inappropriate, shameful, or signs of inferiority. This leads them to hide their symptoms from friends, family, and physicians.
4. The gradual onset of the disease, which is more frequent in children than in adults, may lead the child and the significant adults in her life to think that her low functional level is normal for her.
5. Pediatric CFS, in its early months or years, often does not meet the formal CDC criteria for CFS. Hence the physician rejects this possibility at the onset, and does not wish later to revisit that issue.
6. Many pediatricians and family practice physicians were taught in medical school that the confusing pattern of symptoms typically seen in pediatric CFS is an indication of neurasthenia, a "neurotic" condition.
7. Children have a hard time telling adults what is wrong with them, especially if the adult is skeptical.
8. Many parents are intimidated by doctors and cannot assert themselves if they feel a wrong diagnosis has been given. They frequently lack the time, money, and social skill it takes to negotiate the maze of specialists and insurance company referrals it often takes to reach the large medical centers where most pediatric CFS diagnoses are made.

Great Britain's National Survey into the Incidence of ME in the Schools estimates that pediatric CFS occurs there at a rate of three per thousand. This makes it more common in this age group than cerebral palsy, scoliosis, diabetes, or sickle cell disease -- all recognized as important childhood problems. It is also more impairing than any of these but cerebral palsy. It is important that parents, school staff, physicians, and mental health professionals learn to recognize and help children with this illness.

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Pediatric CFIDS is the topic of the web sites below:

"For Parents of Sick and Worn-Out Children"
http://www.bluecrab.org/health/sickids/sickids.htm

CFIDS Youth Alliance (CYA) Online
http://www.cfids.org/cya