

Diagnosing ME/CFS in Children: One Parent's Perspective

This article is excerpted from the July 2000 issue of Dr. David S Bell's medical office newsletter, the *Lyndonville News* (DavidSBell.com). It is reproduced with kind permission* and the hope it may be helpful for other families seeking a diagnosis and understanding care.

Diagnosing CFS in Children: One Parent's Perspective

by Mary Robinson, mother of three children, two diagnosed with CFS, and co-author with David S Bell, MD, and others of [*A Parent's Guide to CFIDS*](#)

A couple of months ago, Dr. Bell and I were sitting on his back deck talking about children and CFS, and the impact of the CFS diagnosis on their emotional and physical well being. I have always held strong to the fact that the diagnosis is critical in the child's ability to cope with the hardships of the illness itself. Dr. Bell raised several other points for my consideration and suggested I write this up for all to ponder.

My son's road to diagnosis was pretty typical. He saw the "somewhat standard" 10 medical professionals who all questioned us, pondered possible diagnoses and sent him on to the next specialist who would probably have an answer. It ended in a tiny examining room of an esteemed Infectious Disease doctor at a prestigious teaching Children's Hospital when the doctor told him to *get on with his life*.

He spoke to our scared 10-year-old son alone in the room without our presence and told him he knew there was nothing wrong with him. But he offered us the comforting words on departure that if it was CFS, which he had never really seen, then ALL kids were better within 4 years.

We were enraged that this man, this esteemed professional, had totally dismissed all of our son's symptoms and said to get on with life.

This period of limbo that we were forced to go through was emotionally damaging to our entire family. We didn't know if tomorrow would bring the answers we needed so we could treat his condition, or if it would bring the news no parent ever wanted to hear, that our child had a life threatening incurable disease. We lived in a constant state of fear.

Or maybe he *was* malingering and just needed a stiff kick in the pants to get on with life. But whenever I allowed that thought to cross my mind I kicked myself for even considering that this obviously very ill child could be faking these horrendous symptoms.

The educational needs and issues were very difficult to explain when we had no name for his illness. At this point, we were struggling ourselves to understand his symptoms. We were striving on a daily basis to get him into school and to get the teachers to understand what was happening. But we felt this was an impossible task when neither our doctors nor we understood. We felt lost and alone in how to cope with his social, emotional, and educational needs, on top of

his constant physical pain.

My heart goes out to all of you, and I know there are many, who have yet to find a doctor who will treat your child with the understanding and compassion that they need and deserve.

We were very fortunate to find that man. Our son was eventually diagnosed by Dr. David Bell. It was at this time that he became much better adjusted to his life within the confines of his illness. He got into school whenever he was able to manage it, and he pursued as much physical activity and socialization as his symptoms allowed.

- Once he knew what he had, and understood the symptoms and the waxing and waning nature of this malady, his coping skills improved greatly and so did his overall attitude and outlook on life.
- Once we had the diagnosis of CFS and understood as much as we could about the illness, we could explain it to others, in our social circle, and at school. We found a great deal of understanding and willingness to work out a plan that would meet our son's needs.

I do not know how his education could ever have been managed, if we had not been able to explain what was wrong. And the ongoing support and empathy from our doctor was invaluable in educating ourselves and others.

Our daughter entered the world of CFS by a slightly different road.

When we began to notice she was possibly having problems we were already under Dr. Bell, as members of his family practice. So he is not only our CFS specialist but our children's primary care physician as well. His vast experience with treating and diagnosing children with CFS was a comfort to us as we struggled with the possibility that another of our 3 children may be stricken with this illness.

She was only 4 or 5 when I first broached Dr. Bell with this possibility. She had few symptoms at the time, but the fatigue and post-exertional malaise and muscle pain were becoming more prominent. When I would bring her in he would examine her, talk to her, but was not anxious to diagnose her at that point. He was in a good position to "keep an eye" on her progress as her primary care physician, and hoped that she would grow out of this, as many of his youngest patients do.

When Meg entered first grade it became evident that regular school attendance was not going to be possible, and Dr. Bell did a full CFS workup. He had been documenting her symptoms for well over a year at this point, so he had an idea as to the nature and course of her illness. Because of this and the understanding of the waxing and waning of symptoms he did not order a multitude of tests that another doctor may have required.

From the bottom of my heart I thank him for looking at our daughter as an individual and only suggesting tests that were truly warranted by her condition.

He ordered the basic workup and followed up on anything that was truly an anomaly to him.

When the unusual leg pain up the front of her legs by the bone confounded him, he offered to send us to a special clinic out of state for an evaluation. We hesitated, and true to CFS form, the pain disappeared for the next 6 months.

As he proceeded through this evaluation process, he hesitated to call it CFS, and instead diagnosed her with CF, or Chronic Fatigue. This enabled him to follow all her symptoms, [alleviated] our worries and hers by giving her symptoms a name, and fostered in us a deeper understanding of how much thought he puts into his clinical evaluation before diagnosing a child with CFS.

The time eventually came by age 6 when a diagnosis of CFS was warranted. And at this point she clearly had progressed to a level of illness that met the criteria for CFS in adults.

So comes the decision for the clinician, to diagnose or not to diagnose?

What if Dr. Bell had taken the customary role that many pediatricians take and chosen *not* to diagnose our children? Though in his heart he may have understood that there was a connection between the eye pain, stomachaches, sore throats, headaches, leg pains, joint aches, sleep disturbance, activity limitation, and a few other problems, he could not mention that possibility. If he could not diagnose them then he would have to address each symptom in isolation.

That would be tedious, and as a parent I do not think I would be comfortable listing off all their problems. I would probably list the ones that I felt he could help with, like headaches, and leg pain so bad our daughter needed a wheel chair.

If he were to dismiss the symptoms I would feel either he did not believe us, or he didn't care. Without an explanation from him of what was causing the pain I would expect him to order a multitude of tests that would help us rule out the many horrific problems that these symptoms could be a part of. If he did not offer us some explanation I would lose faith in him. I would feel that he must either not care, or just wasn't good enough to be able to diagnose their problems.

I had never stopped to realize though how "not making a diagnosis" ties a physician's hands.

How can they practice good overall medicine, if they can't offer the connection that they see as so obviously a part of the child's problem? A doctor needs to be able to be open and honest with his patients if he is going to be able to build the bonds necessary to really help them. If the doctor has concerns about emotional factors the child's parents are much more likely to listen if they already feel this doctor believes their child's illness is *real*. Once this rapport is built then the doctor can deal with the many issues and symptoms that arise while still keeping an exploring eye out for any other possible diagnoses that could be causing the symptoms.

How many tests are our children put through needlessly just because their doctor does not know what else to do? And if the physician knows it is CFS then how can it be "enabling" to call it that? These children no more "fake" their symptoms than adults do. How can it make a child worse to know that they have an illness?

When a child learns that they have CFS and understands what that means, they can move on with their life.

With both our children it gave them peace to finally have a name for their pain and maladies. They also were then able to be educated about the effect that excessive exercise and activity could have and began to pay attention to their bodies more, to learn the signals of when too much is too much. It didn't cause them to be less active, but more so. They learned to listen to their bodies more, and worry about their pain less.

They became adept at picking friends who were fun, understanding, and less active than their previous friends may have been. They began to have a more positive outlook on life, relishing in their good days, and coping the best they could on the bad ones.

Just having a name made life easier for our children and for us.

It is still hard to explain to the many people we face in our lives, but it is getting easier. There are just so many absurdities with the illness that make it hard for the most open-minded person to understand. But they do. And our children are only the better for it.

School issues became easier to resolve and work out once we understood what was wrong and could explain it to the school. We were able to explain how the orthostatic problems our children had affected their school work, and how their many sensitivities made extended time in a crowded noisy classroom an impossibility. When we could explain their symptoms in terms of the complexity of the entire illness it was easier for the school to grasp than if we had attempted to deal with the multitude of problems they experienced one by one.

Our experience has been that the school has been very willing to help us and provide the best for our children. Having a diagnosis made this a much easier task. I do believe the school would have given up on us had we not had the diagnosis, and the support and letters of explanation from Dr. Bell.

There are children, many children suffering from this illness. And they need to be heard and understood and diagnosed just as the adults do.

May the future offer all those who suffer from this terrible illness and understanding, compassionate and supportive physician, and a person - family or friend - who will listen and understand.

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