



SPECIAL PARENTS

A resource for parents and caregivers of young HSS patients

Communicating to Caregivers

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Nurse, Pediatric Rheumatology

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As a nurse, one often takes more of a role in the day-to-day care than would be expected for a patient. In pediatrics, this role is even more involved in the life of the child and family. Parents often have a difficult time accepting such diseases and understanding the nature of these diseases. Ask any parent of a chronically ill patient and I think they will agree that second to their child's doctor, they seek the advice and guidance of their child's nurse.

As a nurse in pediatric rheumatology, I spent two years working with children who had conditions like JRA, SLE and a whole host of other rheumatic diseases. These are difficult diseases to deal with in the physical sense, but they also present other challenging social and psychological issues. I found that parents and siblings bear much of the burden of these diseases, as with many other diseases.

Specifically with these physically challenging conditions, I found it was often difficult for parents to convey the needs of their children to outsiders including teachers, coaches, babysitters, parents of friends, etc. Often, it was better for a health care professional to talk to such people so as to provide perspective.

I recall one family in particular. The parent was so overprotective, it was interfering with the ability of the child to lead a normal life. While it was all out of love and with the intention of protection, it worked negatively on the child. This parent was not allowing her child to participate in certain sports which actually may have helped ease the child's pain. Upon the parent coming to me as a confidant, I assured her that I would give strict instructions to the would be coach as to what the outer limits of the child's participation should be. This actually proved to be extremely positive to the whole family unit.

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Letting Go by Ann Gottlieb, parent

"Looks like it's Juvenile Rheumatoid Arthritis". With those words, our family pediatrician sent my mind into a surreal state regarding my four year, nine month old daughter, and how all of our lives would be changed forever. Weeks spent reading up on the disease, listening to every friend of mine tell me it's ok, and some friends who would feed into my fears that this was the worst thing ever, learning how to explain to my little girl why she had to take her medication and why sometimes she hurt when she got up in the morning...Our heads spinning, as our daughter played throughout the house, having a grand old time.

It didn't take long to realize that all this, like everything else in life, can be somewhat organized, dealt with and basically, put in perspective. We approached her arthritis as a group experience. Our older daughter gave her sister her medications and made sure to have a close watch over her when playing with the neighborhood kids. Grandparents were all educated about the disease and explained why she would get so tired and, no, it wasn't because she was lazy. All this ended one month later when our little one asked, "Can I do that?" Less than five years old and she was already taking an active role in the administration of her medication. I must say I was impressed.

So my life was set. I was now the mother of a special needs child, and I could do it. She was with me all the time so I could take care of her and protect her. But then it hit me...what about nursery school, day camp, visiting friends? I soon realized that my greatest concerns were not taking charge of her needs, but letting her leave my arms and eyes-no longer in my control. The thought of keeping her home from school and insisting that any play dates would be held at our home, were thoughts that entered my mind. Then it hit me again. Who was I kidding? I wanted to allow her to lead a normal life and I was doing one of the things I hoped that no other kids on the playground would ever do: I was the one making her different. Not the disease.

And so a scenario was put in place that helped me throughout her young years. A simple list of "do's", "don'ts" and "what ifs" was given to anyone who would be "in charge". Every fall I visited her new teacher. Every summer I visited the new camp nurse. As new friends were made through my daughter's school and camp, I always gave the parent "the list". This seemed to put everyone else at ease including myself. Teachers, camp personnel and friends always went the extra yard to make sure special activities were available if necessary at parties, outings or just the occasional visit.

When my daughter entered second grade, I did what I never thought I would be able to do. I went back to the profession I love, teaching. Throughout my educational career I have had many special needs children. My daughter gave me insight, understanding and compassion to help children, especially those deemed "special", as well as help ease the fears of parents first letting go of their children for a day at school under someone else's careful watch. She helped me to comfort a child whose body was riddled with pain from leukemia. She inspired me to work in tandem with a school nurse to help a young boy as he went from crutches, to wheelchair, to total dependence because of muscular dystrophy and to work with a little girl with cerebral palsy.

Amazingly, it's been over twenty years since the pediatrician spoke those words to me. My little girl has grown into a truly remarkable woman who no doubt will someday change the world.

Communicating to Caregivers, continued

Another instance involved a child who was so convincing that he would push to those outer limits where he should not have done so. The father of this child wanted so much for him to be like other children, he failed to accept that his child did have limitations.

This child did participate in the same sports, almost to the same degree as others his age, but clearly was not capable and may have compromised his health. After successful intervention, the father trusted my judgment and allowed me to speak with the coach.

My advice? Engage your child's health care team in teaching those who will have responsibility for your children. If you are too emotionally involved, sometimes the message gets cloudy.

Real Coaching *J. Bond, High School Administrator and School Coach*

Sports have also always been a passion for me. My success was limited to playground pick-up games, playing with friends and making my high school JV basketball team. I spent the first 22 years of my career teaching students who had learning disabilities, emotional problems and physical challenges. My first year as a high school teacher brought me to the big leagues...girls' basketball. From there I coached soccer and then spring track. It was in this last sport that I realized what coaching really was in terms of working with young men and women.

While we were a track team, it was made up of individuals who competed in individual events. With the exception of our relay teams, you had only yourself to depend upon for your success. That dependence included everyone, including coaches. One of my students also had a talent that few in the school possessed...she was strong, competitive and extremely fast. Her emotions were also fast as they were always on the surface and at any given time she would lash out against anyone. Her challenge everyday was to "get through it". My challenge was to make her into a student athlete who would begin to see how unique she was.

Through a great deal of work during the school day, consisting of personal conferences about her as a person, about her problems in school and at home, about her natural abilities and about her positive traits (there were many), this young girl began to grow into a young woman. As her coach, I pushed her as hard as I did her teammates and made the decision to put her on one of our relay teams...a big step for her for now as she had to function as a part of a team, not just as an individual. Accepting constructive criticism and any help months before would never have been possible. Now, she was able to quietly listen and make adjustments to enhance her track performances.

So how does this story, while inspirational for parents with children with special needs, really relate to a newsletter for parents and caregivers of HSS patients? Because I am one. I truly believe that my experience coaching is what helped me 15 years later when my own student athlete was diagnosed with JRA. My own daughter, an accomplished basketball player soon lost the stamina and physical capability to compete. Not only would I do anything to take away her pain, I wanted to do anything and everything possible to encourage her to be the best that she could be, even if it didn't involve a basketball.

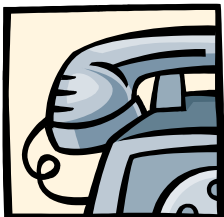
Her time spent mourning the loss of her inner athlete was short lived. We have no doubt she would have come as far as she has on her own, but I'm proud to say my daughter to this day credits my wife and I to helping her

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HSS Pediatric Social Activities Calendar

June 2004- October 2004

Children's Halloween Party, October 29, 2005, 3:30 to 5:00 pm



Please RSVP by calling the Pediatric Special Events Response Line: 212.606.1959.

Real Coaching continued

cope with the RA and the impact it has had on her life. She still calls home for some "home coaching", as she calls it, when things get tough, but I know (and try to help her to know) that she truly can do anything she wants to.

More than 20 years have passed since my track star graduated with her teammates. All of us, thanks to email, still keep in touch. This particular young woman still bounces ideas off of me about her current life, about children, about being a parent. In the end, I believe I learned more about myself as a parent coaching her in track than she did from me.

Contact Us....

SPECIAL PARENTS is a resource for parents of young HSS patients. We would like your ideas and suggestions. If you have a parent experience to share, or information you would like to see in upcoming issues, please contact:

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The next **SPECIAL PARENTS** will be available in November 2004. The deadline for contributions is:

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SPECIAL PARENTS

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