



Complex Child E-Magazine

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PTSD in Children with Special Needs and Their Caregivers by Michelle Doty

"Anyone can give up, it's the easiest thing in the world to do. But to hold it together when everyone else would understand if you fell apart, that's true strength." - Christopher Reeve

Shortly after my daughter Campbell's first medical emergency, I noticed that I was much more agitated, anxious and always on alert. This caused me to suffer from insomnia, panic attacks and depression. I began talking with other parents and did my own research, finding I was not alone.



As I was researching how parents and children coped with multiple hospitalizations, I kept coming back to information on Post-Traumatic Stress Disorder (PTSD). Could I have this? Could Campbell have this?

Campbell's Story

I remember very clearly the first medical emergency I experienced with my daughter, Campbell. She was born with a bilateral cleft lip and palate, which was undetected on ultrasound. Campbell was born in January, and since we were unprepared for all of the appointments and medical care her cleft lip and palate required, we felt rushed to get everything planned out for her treatment. My first goal was to get her an appointment with a craniofacial surgeon. The only number I was given was to our cleft lip and palate program at the state's commission for children with special health care needs. I quickly made her an appointment to see the surgeon when she was only three weeks old.

On the day of the appointment, my husband and I took Campbell to find a waiting room packed with children and adults all waiting to get in to see the doctor. It was a first come, first serve situation, so having an appointment really didn't matter. With it being prime cold and flu season, several people in the waiting room were coughing and sneezing. I moved over to a less populated side of the room but it didn't matter. Two days later, Campbell had Respiratory Syncytial Virus (RSV), which is a common respiratory virus, but can be life threatening to young babies and those in certain high-risk groups. Before I knew it, she was being sent in an ambulance to the nearest children's hospital to begin what turned into a 16-day hospital stay. Ten of those days, Campbell was in the pediatric intensive care unit (PICU), with five days on a ventilator.

During her hospitalization, we frantically called our priest to have her baptized in the PICU. With RSV, it is a roller coaster to say the least. Children can appear to get better and then drastically get worse. Due to overcrowding, Campbell was ping-ponged back from PICU to the acute care more times than I would like to remember, until she came extremely close to coding and the doctors finally took her condition as being serious enough to keep her in PICU. Campbell was poked and prodded so many times that they had to call in the medical flight nurses and even anesthesiology to find a vein. She had so many arterial blood gases taken that they had to do some in her forehead.

The beeps from the machines, watching all the numbers on her monitors constantly, and listening to the doctor's reports made for a complete information overload. I heard things like, "This is very serious and we just don't know what will happen," or, "She isn't responding like she should," when she didn't wake up after being on the ventilator.

Fortunately, Campbell improved and was able to return home after 16 long, stressful days in the hospital. Little did I know that this was just the beginning of her special and complex medical needs. Campbell is five years old and has had four ambulance rides, multiple hospitalizations, and five surgeries. She has minimal hearing loss, cortical vision impairment and significant hypotonia. She is classified as having an unknown genetic syndrome, which adds another barrier to her medical care since nobody knows exactly what is causing her symptoms.

PTSD in Caregivers

After that first hospitalization for Campbell, I had several symptoms, such as trouble sleeping, irritability, trouble concentrating, and avoiding talking to people outside my inner circle about the incident. When I tried to go to sleep at night, I could hear the sounds from all of the machines in the hospital room. There was an artistic display in one of the waiting areas that was like a Rube Goldberg machine. It made a repetitive sound that I could not get out of my head. Every time we go back to that hospital and I hear that noise, I get a sense of panic and feel like I am right back at that time. Even now, almost four years later, I can still hear a similar noise and will try to avoid it due to the reactions it causes.



Were these symptoms of PTSD? Having a child with complex medical needs has allowed me to speak openly with other parents in similar situations and obtain additional information about this subject.

Interest in PTSD increased in the late 1970s as Vietnam veterans returned home from war. The term is now applied to other trauma survivors. It occurred to me that people who have medical emergencies or repeated hospitalizations are also at risk for developing PTSD. So are their caregivers.

As I was researching, I could not find a lot of information specifically on PTSD in relation to parents of children with special needs or medical complexity. It is definitely an area that needs to be researched more in depth.

The following are symptoms of PTSD:¹

- Flashbacks or reliving the trauma
- Nightmares
- Avoidance of talking about incident
- Feeling emotionally numb
- Avoiding enjoyable activities
- Hopelessness
- Memory problems
- Trouble concentrating
- Difficulty maintaining close relationships
- Irritability
- Guilt
- Insomnia (trouble sleeping)
- Easily startled or frightened
- Feelings of panic
- Startling

These symptoms often appear just after the traumatic event, but in some cases they might occur years later. High stress or exposure to certain stimuli might trigger symptoms.

PTSD can occur from one single event, but can also happen from repetitive or prolonged incidents. The trauma can be ongoing with a child with chronic medical needs. Having the fear that something might happen at any time can be extremely stressful. Unpredictability that the event will occur again can make the situation worse. With Campbell, she can have several months where she is without any illness, and then out of the blue, she has an unexpected hospitalization. That looming fear of another traumatic event is often lurking in the back of my mind. It makes me feel like I have to constantly be on alert.

PTSD in Children

Another thing that I questioned was, "What effect does this have on Campbell?" Like I mentioned earlier, Campbell has significant delays. She is non-verbal and is classified as having cognitive delays. In addition, she is still very young. The majority of her more significant medical emergencies occurred before she was three.

Looking back, I can see many of the symptoms of PTSD not only in myself, but also in Campbell. I think it is especially hard to tell if these symptoms are a result of a reaction to the stressful event or just a symptom of the medical condition itself. For example, Campbell has had difficulty sleeping since she was born. She was often a fussy baby, but I related it to reflux. While some of these may have been related to medical conditions, I also have to wonder if they were related to her multiple hospitalizations.

I started to really observe how she reacted before and after medical events. I noticed that she was easily startled and frightened following a hospitalization. She also became very clingy and afraid to leave me in the weeks following a medical emergency. During a planned surgery this past year, I really noticed her awareness of what was going on. The fact that she is non-verbal compounds the symptoms. She was very agitated, crying, and startling during the pre-operative phase. For the hour prior to the surgery, we could not calm her, and she eventually needed a medication to relax her prior to anesthesia. This made the entire experience much more stressful for all of us. I also think that she could sense the feelings of anxiety that both my husband and I experienced with her surgery.



When we returned for her post-op visit to the doctor, she screamed in the waiting room and then pushed the surgeon's hand away when he went to examine her sutures. She had never displayed this type of behavior before, and I began to realize that she was much more aware of what was going on than I thought.

I began to talk with her and prepare her prior to procedures and doctor's visits. It has really made a huge difference. If Campbell started getting upset, I made sure that I explained to her what was going on and that Mommy would be there with her. Just the

other day, she was crying and I knew it was her stomach that hurt because she had been constipated. I said, "Campbell, Mommy knows that your tummy hurts and you need to go to the bathroom. I know that you are trying to tell me even though your words cannot come out. I am giving you some medicine to help your tummy." She immediately calmed down.

I know that I underestimate her ability to understand and her need for support in dealing with trauma as well. I try to remember that for all the trauma that I have experienced by observing her medical emergencies, her experience of the same events is tenfold. She is the one who has been operated on, pricked with needles, taken into a cold and unfamiliar operating room and intubated with a ventilator.

Getting Support

I think one of the biggest things that has helped me deal with the stress I have experienced is talking with other parents. Just knowing that there is someone else who has been in my shoes or is going through a similar situation lets me know that I am not alone. I think the main thing that convinced me that it is all right to ask for help is the realization that if I don't take care of myself, I can't take care of two children, including one with significant medical needs.

I often say that during periods of intense stress that I go into survival mode by just getting the basics done. It is one thing to cope with your symptoms, but another to actually overcome them and recover.

I will admit that I have not had any counseling, but I know that I would benefit from it. I think that having a neutral, outside view is essential in overcoming some of the symptoms of PTSD. Standard treatments include medication, cognitive and exposure therapy, eye movement desensitization and reprocessing (EMDR) and cognitive behavior therapy. Support groups are also very helpful. These are just a few strategies to help recover from PTSD.

Despite having significant difficulties, not everyone seeks professional help. Often it may be due to lack of insurance or other resources including time. There are multiple options for treatment that can be discussed with your doctor, since each person's situation is unique. The main point is to know that there is help out there.

Other parents have told me they also experienced many of the symptoms listed above in themselves, as well as in their children. The more hospitalizations and the greater intensity of the medical emergency, the more symptoms were experienced. Many of the other parents felt that over time it became easier to deal with the repeated hospitalizations. However, other parents including myself felt that it really doesn't get any easier due to the variety of situations and the unpredictability. During a recent trip to the ER by ambulance with Campbell, I still had that panic feeling with insomnia, irritability and difficulty concentrating following after.

Acknowledging that our children also need support, whether it is professional counseling, child life specialists, or social stories, is a huge step. Knowing that your child is relaxed and not frightened will help reduce your stress as well. Of course, things like diet, exercise and other relaxation methods will help in relieving stress overall. It really needs to be a whole family approach. Even my 11-year-old son has experienced symptoms of PTSD. Every time he sees an ambulance, he says, "Someone is having a seizure."



What I learned from exploring this topic is that there is a lot of research that needs to be done on PTSD in relation to parents and children with complex medical needs. It is important to point out that it is especially critical to investigate strategies for non-verbal children. For example, Campbell's new communication system allows her to indicate if she is hungry or tired, among other things. We also use social stories.

It is critical to reach out and support one another. I am not a professional psychologist or physician. I am just a mom who has experienced what it means to care for a child with complex needs. I am fortunate to work with other parents as a family service coordinator and as a member of multiple support networks. Making that first step is the biggest obstacle, but talking with someone can be a huge relief. As American poet Emily Dickinson once wrote, "I felt it shelter to speak with you." I encourage those who suffer from chronic and intense stress to find shelter in one another.

For more information, check out *Invisible Heroes: Survivors of Trauma and How They Heal* by Belleruth Naparstek.

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¹ From <http://www.mayoclinic.com/health/post-traumatic-stress-disorder/DS00246/DSECTION=symptoms>