



Complex Child E-Magazine

www.ComplexChild.com

Raising Healthy, Happy Siblings by Shannon Gonsalves

Our oldest daughter Hannah spent almost two and a half years as an only child. It was just the three of us going to the zoo, beach, park, putting together puzzles, coloring, or reading stories. We spent a lot of time each day just simply enjoying her happy, bubbly personality.

We began preparing her for the addition of a baby brother, and even moved her into her very own pink bedroom that she helped us set up. Following the advice of professionals, we did this early on in the pregnancy and didn't use her brother as the reason for having to give up her crib. Everything was progressing quite well.

Babies in general require more time and care than an older child. Rationally, we knew this and began the process of preparing Hannah. Nothing, however, could have prepared any of us for the premature birth of Hannah's brother, Caleb, and the subsequent care that came with caring for a preemie with health issues.



An Unexpected Complication

For two and a half weeks, every three hours of every day, I would head to the hospital to drop off more pumped breast milk and help care for Caleb in the NICU. After spending about an hour in the NICU with Caleb, I would drive back home to spend about an hour with Hannah before it was time to pump and head back to the hospital again. In the evening, we would all head into the hospital to visit with Caleb.

This hectic pace is how the next four years of his life has continued. Always, in the back of our minds were two thoughts: gratitude for a very independent and bright daughter who needed very little of us, and the need to watch closely to ensure that we were keeping things psychologically healthy for her. Hannah was so self-reliant that it became very easy to put her on the back burner while we cared for Caleb's many health needs. She has been forgotten many times, unfortunately.

Concerns for the Sibling

Even being very careful to give her whatever time we could, Hannah's behavior has started to become concerning in the last year or so. Her personality changed to very quiet and shy, and she tried to hide her emotions. She was withdrawn at times, and even her kindergarten teachers set goals for her to be more carefree. At home, we saw tantrums and attention-seeking behaviors as well. More than anything, the thing that clued me in to the problem was that she was getting angry when Caleb needed me the most.



I met with the school psychologist and was told that it's not surprising for her to have grown up faster and to be exhibiting these behaviors. She has seen way more than most kids her age might ever see in their adult lives. It made sense, but it made me sad to think

that our bubbly and happy toddler was now a very quiet, serious child. She still had happy moments, but her personality was definitely different from how it was before Caleb was born.

Ways to Include the Sibling

There are many things parents can do to ensure that their other children all have what they need to grow up happy. Different personalities and situations might still mean that your child needs more than these simple ideas, but everything you do helps. Here are a few ideas:

Special Toys

My son has a feeding tube in his tummy. When he first got it, we took him to Build-A-Bear with an extra tube and had them sew one in a special bear for him to feed. We kept noticing that Hannah would sit by him and quietly wait her turn to use his bear, too. It never dawned on us that she'd want one as well. So, we got another tube and went to Build-A-Bear to make one for her. It made a huge difference and also helped her feel special. She even took her bear to preschool for show-and-tell, which was a coveted event.

Looking back, we realized how many times Caleb received special toys or treats while his sister got nothing. Every time he went to the hospital for an appointment, test, or procedure, they would shower him with goodies. Hannah NEVER said a thing. That is her personality, as she tends to internalize everything until she blows up.

To even out this imbalance of special treats, I'd have a special treat waiting for her too when we knew Caleb was getting a goody. I kept a goody box at home stocked with clearance toys or dollar store goodies that I would pull from as needed. After inpatient hospital stays, Caleb always managed to acquire many new toys from nurses or family. Right before coming home or if she was able to come visit, I'd go to the gift shop and get Hannah a special balloon and treat for being such a wonderful sister. It dawned on us that she was going through the stress of this hospital stay as well, but was not being recognized for it like her brother was.

Special Routines

Caleb has many scary medical procedures that are done to him, and they tend to make him clingy at times. He really needs us during those times, and would often monopolize our time. For example, when he had his NG feeding tube, we had to place them at home. It was a horrible process that involved restraining him while my husband shoved a tube down his nose and into his stomach. Afterward, we'd have to tape it to his face and then take the old tape off the other side. The whole time we did this, he would scream, his nose would bleed, or he would throw up. After it was all over, he would sit in my lap traumatized for at least 45 minutes to an hour just snuggling until he felt better. We would often put his favorite movie in to distract him.

Hannah would sit there watching us do all of this to her brother. However, we were so focused on him that we forgot how scary it might have been for her. Once we realized this, we started to prepare her ahead of time by explaining how he might react and why we had to do it to him. We would give her a job to help out and then all three of us would snuggle up on the couch afterward with a movie.

Typically, after a hospital stay or during an illness, Caleb would be too fragile to sleep in his own room and would sleep with us. This was VERY difficult for Hannah who, given the chance, would be sleeping with us nightly. So, we started having sleepovers in our room for both kids every now and then. Every time Hannah got sick, we'd put a mat in our room for her as well. Did she really need to be in there? No, she didn't. She would have been fine on her own. However, it made a huge difference to her. We saw a drastic improvement in how she would react when Caleb needed his mat moved into our room.

Alone Time

A lot of information is out there about parents of special needs children needing alone time to regenerate and get away from the hectic pace of life. The same is true for our children who don't have complex needs. Take some time to get out alone with your typically developing child. Go for a walk, take her to lunch, volunteer in his classroom, or surprise him at school for lunch. Make the time to be alone with your child. Keep it light and fun.



Respite or in-home care for your child with medical needs is another option. This is what made alone time possible for us, and the insurance company even paid for it! Like many

parents who have children with medical needs, my husband and I have to work opposite days to be able to both work and provide care for our son, leaving little time for Hannah. My husband works every weekend when I am off with both kids. Getting Medicaid caregiver hours made it possible for me to leave Caleb alone at home while Hannah and I went out to do something together.

If you can't get caregiving or respite care, consider occasionally pulling your child out of school for short times. Will it really hurt your child to miss a school lunch or recess, so that the two of you can go out to lunch together somewhere special? It can be something as simple as showing up unexpectedly to his school with a special lunch to share at school together. In addition, this was the only place I could fit in counseling. I pick Hannah up 30 minutes before her lunchtime twice a month. She misses her lunch and recess, but it's time that she actually enjoys with me. It's not just counseling to her.

See if your family would be willing to be trained in your child's medical needs to help give you alone time with your other child(ren). In our situation, this hasn't worked out as well since many are not comfortable with his care. Instead, we've asked that they take Hannah to special events with them. We've had days when Caleb has done nothing but cry or whimper in pain, and while it wasn't easy, I would call around and find someone who would get Hannah away from it for awhile.

Model How to Handle Stress

Our kids will learn how to handle stress by watching us. If you start arguing more with your spouse, then your child learns to yell to get it out during difficult times. If you shut down, your child sees shutting down as an option. The same holds true for a parent who chooses not to take care of herself. Your child will learn that she isn't equally as important.

Teach about Fairness

A mistake that many parents make is to teach their children that fair means equal treatment. Fair doesn't mean equal, it means ensuring that everyone's needs are being met. How that happens is very different for each child and situation.

We have deliberately taught this to both children. Caleb doesn't need to eat some of his dinner to have dessert, but she does. She knows that he is getting his dinner in his feeding tube. This is fair for both children. If you try to keep up with "equal" for all your children, you will be running in circles and possibly even spending unnecessary funds. Many parents stress themselves out trying to keep things equal when that isn't necessary.

Incentives and Rewards

This one was harder for me. I have my bachelors degree in childhood development and it was drilled into my head that children should learn intrinsic motivation rather than extrinsic. Praise should be enough of a reward for a child. However, as much as I knew this is what the textbooks taught me, Hannah needed something special just for her.

Our incentive program uses cheesy little plastic coins that are shiny and say, “Caught being good” on them (\$4 for 100 coins). As a family, we decided to use them as currency in our Family Store. Together, we came up with a list of things that Hannah might want to “buy” from us. We kept them very simple and as experiential as possible.

For example, she can trade five of these for a cup of hot chocolate, which I make at home using chocolate Silk and heat it up in the microwave. She doesn’t seem to care that it’s something she could have on occasion without the coins. An example of an experiential treat would be 10 coins to play a game of your choice with the parent of your choice. 20 coins can be traded for mom or dad coming to lunch/recess at school.

This has made the biggest difference in her life for several reasons. First, both my husband and I can get very busy and forget to praise her often enough. It’s easy to ignore the easy child. A pocketful of coins reminds me that I haven’t praised her enough. I begin looking for the good and always can find it. I just forget sometimes to look. Secondly, when things get really overwhelming, it forces us to schedule alone time with Hannah. It also gives her power and a safe way to demand our time. There are many items on the list that will give her alone time with one of us or even on her own. We actually have “alone time” as one of her options and she often chooses it. It’s time when we will keep her brother away from her and just let her play alone.

Get Help and Support

Even if you do everything that you can to give your child the right amount of time and attention, it may not be enough. Depending on your situation, your child may be witnessing things that his friends can’t relate to or he might even consider to be embarrassing.

As an adult, I belong to an online support group for parents who are raising a child with complex needs. Many of the discussions mention how these moms can’t relate to typical moms and really need this support group to vent. However, many siblings have nowhere to go and are worried about being an added burden to their parents.

Ask at your hospital if there is a support group that your child can join to meet kids in similar situations. In our area, the ARC does Sibshops, which involve dropping off your sibling to spend time with other children in similar situations to do fun activities. They also provide education and resources.

Also consider looking into family counseling. Hannah and I recently started going to a counselor together. Twice a month, we play games and the counselor helps us relate better by pointing out important tips to me. It doesn’t mean that I failed Hannah or that my ways of keeping her included didn’t work. I know that every little bit helped her. However, I also didn’t want to wait to get her into counseling when it was too late. Right now, it’s not critical, but I could see us heading down the wrong path in the future. Counseling isn’t a failure or last ditch effort. It can be proactive.

Don't Ignore It

No matter what you do, keep in mind that the sibling of a child with complex issues really needs complex care too. Your child without complex needs also needs the things that you need as an adult to function normally. Raising a healthy, happy sibling needs to be as deliberately planned as administering medications to your child with medical needs.



No matter what, be careful not to ignore that well-behaved, quiet, self-reliant child. A child who isn't getting enough attention to thrive will accept negative attention just as readily as positive. He may do anything to get that negative attention. Don't assume that they don't need that little extra TLC.