

Parents Coping with Relapse

After our child was declared disease-free—after about ten months of treatment and some of the ugliest side effects we could have ever imagined—we felt secure enough to delve into the NB community and see what was going on out there. We had been through the dark forest and felt like we were coming out the other side and seeing glimmers of light. We never doubted the treatment, and said we had no concern for survival statistics because we were hopeful and faith-filled people and knew she was going to survive no matter what

In reading so many stories online and in papers every night, we would lament the number of kids who relapsed and asked ourselves this very poignant question: “*What’s worse, original diagnosis or the news of relapse?*” This question was something that gave us hours of conversation, and it seemed relatively easy to discuss at the time, because it was always someone else’s child.

While we had absolutely genuine sorrow for the family, it still wasn’t that feeling of having the wind knocked out of you like when *you* get such news. It was almost therapeutic to have these and other conversations because again, it wasn’t in our back yard and as long as we were big enough to discuss it, it felt like we were staying informed and didn’t have our “heads in the sand.” However, fearful as if just saying it would make it happen, we never said, “What would *we* do if *our* child relapsed?” As foolish as that may sound, we can at least reflect on those times and know now that we had real concern of the chances of a relapse occurring, and by discussing other children we tiptoed around the edges of our own fear.

We never really answered that “which is worse” question, and as best as we can tell, there is no right answer. Both original diagnosis and news of a relapse are devastating events, and while everyone deals with the two differently, there are some inherent truths about both that make them tough to swallow.

At original diagnosis, your biggest fear is the unknown. After all, before diagnosis, what was your biggest exposure to the world of pediatric cancer? Maybe you watched a St. Jude’s Hospital fundraiser for ten minutes and said “gee that’s sad, those poor kids.” Consequently, it was disturbing to look at and you changed the channel to see what else was on. Unless you were a woman looking for a real good cry and in that case, it did its job because it is in fact sad. So while often people say ignorance is bliss, not knowing the next step when your child is diagnosed with cancer is anything but blissful. It is probably the most frightening event of your life.

In the case of relapse, however, you have still more complicated feelings and fears. You may think, “if I ever get that news, I can handle it, after all, I’ve been through the Neuroblastoma protocol, I’ve seen everything.” **Not so!**

When we first got news that our daughter had “*suspicious findings*” on her CT scan, we experienced a whole new range of emotions and none of them were good. Thinking back to all we had read and people we had met, we knew how serious this was, and for the first time, we had to face the question, “What if she has relapsed?” No more tiptoeing around the edges, this was here and in our face and the security blanket of discussing hypothetical situations and other people’s kids was ripped away. In facing the possible news of relapse now, there were many layers of fear and concern. Some things were anger and frustration about why she had to go through this again, hadn’t she been through enough? After a year of brutal chemotherapy, transplant, radiation, and the antibody therapy, it seemed she had paid her dues.

Other things were more pragmatic like, if our daughter had relapsed, who would travel to our cancer center in another state with her for treatment; who would pick her sister up from school every day; and what about her education? The problems of one of us quitting our job and restructuring our bills were also concerns.

But none of these issues rang out as loudly as the feelings of guilt and helplessness that arose. We thought we did everything right: we gave all her meds on time, attended every hospital appointment on time, kept her isolated from germs for months on end when necessary, and even chased down an experimental antibody therapy all the way across the country that our insurance wouldn't cover—yet she relapsed anyway. Did we put her through all this hell for nothing? Helplessness certainly sums up those feelings, and there was nothing we could do about it, but go back to our cancer center and face the music.

As mentioned in the beginning of this essay, we are a hopeful family and do not make our decisions based on statistics and percentages. It was hope that carried us to our cancer center in another state, the final stop on our journey from *maybe relapsed* to *starting treatment* for relapse. Even on the day of our daughter's surgery, we sat for hours on end talking about the possibility of the tumor being a ganglioneuroma, a benign mass that the surgeon could remove and then we would go home. After about five hours, the surgeon came in to tell us that it was in fact Neuroblastoma, and down came the ton of bricks. No more maybe this or maybe that, this was in-your-face cancer relapse, and it was every bit the kick in the stomach that the original diagnosis had been.

Once relapse is confirmed, the issue becomes how you *choose* to deal with the new world you have just been shoved into. Your perception is very powerful and your outlook is equally important, so the actions you take from day one may really be the true measure of your child's success in fighting "Round Two" of this horrible disease. Are you going to listen to the naysayer's stories of doom and gloom, or succumb to statistics (that in almost all cases are at least five years outdated by the time they are published) or are you going to grab your child's hand and muster up all the courage you have, and tell the doc, "Let's go, we're ready to fight"? It seems the answer is a no-brainer, but it's not always that easy—fear seems to weaken people, and if you give in to the numbers, it can be the beginning of the end right there.

So, once the crying was over, it was time to get it together for our little girl, and that meant putting on the war paint, and *fighting*. Of course our part of the fighting was the easy part; it was this poor little child who was going to go through the torturous therapy involved in treatment of relapse Neuroblastoma. This may be where relapse becomes tougher news to digest than original diagnosis.

In the beginning we were ignorant and didn't know what to expect other than what our doctors told us. But having lived this life for some time now, we knew how toxic the chemotherapy was, we knew her counts were going to drop, we knew she would once again be susceptible to infections. Now we would have been thankful to be ignorant and not know what we were about to put our little baby through. The good news in it all (if you can call it that) is that we've been through this before. We have no illusions or misconceptions about what's to come, and we have the resources of a caring medical team that has become, in effect, a part of the family. This combined with all of the other support systems both in person and online, makes it possible to take on another day, and do it with a good attitude.

As we sat with our doctors, things became a little more settled, and while we were upset about the circumstance, how much can you really expect to resolve by being mad at cancer? So, the treatment plan was laid out, we resolved the logistics for our home life, and all that was left was to try and explain it all to our little five-year-old who was waking up with a belly full of stitches. She came back with things like "Why did the doctor cut my tummy? I'm not sick", and "Why do all those kids have no hair?" So as you can see, there are many more ingredients to relapse than just the medical facts and treatment protocols.

We have always felt that attitude, hope and faith (and not in that order) are integral parts of fighting cancer. Very early after original diagnosis, we wanted to know everything and were charting our own drugs and terrorizing the nurses for every morsel of information when the doctor told us this: “Let the doctor’s do what they do, let the drugs do what they do. Your job is to be a parent and keep your child safe, secure, and happy.”

Anyone who has met our daughter knows that not only will this advice stay with us forever, but that it has proven itself. Any four-year-old who could run into an IV room, and put her arm out for a series of sticks into her vein depleted little arm—laughing the whole time and insisting that the parents wait outside—is a child whose parents did their job.

Please contact info@cncfhope.org with any comments