

One Family's Insights

If you are reading this, then you already have felt the horror that comes with hearing the word Neuroblastoma. You may have gone through weeks or months trying to figure out why your child has unexplained fevers, or a limp that comes and goes. Or maybe there was a sudden change and a quick diagnosis. Whatever the facts, not one of us will ever forget that minute our world changed forever. The goal of this essay is to let you know that many have been down the path you are now on. We are sharing our observations to help you understand the feelings you may be experiencing, and to let you know you won't be in this state forever.

Once a diagnosis of neuroblastoma is made, there are often quick decisions to make concerning treatment options. The immediate shock of what you are facing can manifest itself in actual physical symptoms. Many parents report that they were physically ill—shaking, vomiting, or fainting during the first week of diagnosis. Try to remember that there is a lot of hope, a lot of promising treatment ahead. Relaxation and breathing can calm the mind and provide a temporary focus when your head feels like it is swimming in information. Taking a few moments several times a day to do relaxation techniques can help your physical symptoms, and put you in a more focused place emotionally.

This may be the first time you have ever faced with the types of decisions and challenges that you now are confronting. Doctors are giving you important information and you must think and make decisions while still reeling with fear and disbelief. You may feel absolutely overwhelmed. When meeting with doctors, it is very important to have someone with you so that discussions can be processed by two sets of ears. Don't be surprised if your short term memory is a little challenged--having someone else participate in these conversations, especially at first, will give you more of a sense of control.

The new learning curve you are on is much more manageable when you have support. Learning the routines of treatment, communicating about this with loved ones, entertaining your child for long stretches of time in the hospital, these are all new things for you to cope with. Don't be afraid to ask for help! People will offer to help, but may not know what to do. Tell them how to best support you! If you are unsure yourself of how others can assist your family, see the section "Reaching Out and Accepting Help" for ideas. There are no right or wrong ways, find what works for your family.

No one can imagine having to tell a son or daughter that he or she has cancer. The courage you find inside to be upbeat and positive in front of your child often turns to outrage and anger when you are alone. Parents of very young children may find themselves inventing words to help little ones understand the word *cancer*. Babies and toddlers have no frame of reference to understand cancer, so they really don't know what they are facing. You have to build a new world for them quickly, making up words and analogies to help them understand. You may be surprised at how well they adapt to treatment.

If your child is old enough to know someone who has been sick, then the conversations become a little more delicate. Around your child it is helpful to use simple terms. They need to know they are getting medicine to help the cancer go away. If they have experienced someone dying, give them a story of a survivor to focus on. Don't feel you have to go into great detail. Children are very concrete thinkers. They most likely will want simple, comforting explanations. Take each day as it comes!

Telling adolescents and young adults is also different. They understand the word cancer. They have prior experiences; they know cancer can mean death. Telling a teen or young adult of his or her

cancer diagnosis puts parents in the difficult position of dealing with their child's emotional response to a situation they themselves have likely never experienced.

It is difficult to know how to be most helpful as you struggle to explain to your child something that you cannot really explain to yourself. Focusing on the concept that you are a team and that you all will work together, emphasizing he/she is not alone, can be helpful. Even stubborn teens may become very needy and are thankful to know that your support is unconditional. Their emotions are all over the place. Try to react to their ups and downs with a steady, loving presence.

For all ages, sometimes the best thing to do is to just be there. Although it is hard not to take your child's reactions personally, try to remember that the combination of pain medications and chemotherapies creates temporary personality changes that are not to be taken to heart! More than one of us has cried from hurt feelings, but try to hold on to the fact that it is all temporary. When your child's fear shows, just being there and validating your fight together as a family is very comforting. Telling your child about other kids that are out of treatment and living a "normal" life again can help him or her create a vision to hold on to.

It may help to understand that you are probably going through a time of grieving. You may be mourning the loss of a seemingly healthy child to one whose future is not certain. You may be grieving the loss of being together as a family. Treatment often requires the family to be separated. Siblings may be shuffled around; spouses spend days, weeks, and sometimes months separated. You may be grieving the loss of a job. Friendships fade, new ones form. Extended family may or may not be helpful. You may feel you are facing the loss of everything you knew as your world. There is no longer the comfort of routine. Your life is on high alert at all times as you respond to the unpredictability of the illness and its treatment.

At first most of us feel incompetent and very unsure of ourselves when it comes to the new tasks we are handed. Please know that it isn't easy to assimilate new things in life even when you AREN'T grieving. Given the possibility that you are in a state of grief on top of trying to become quickly competent, sometimes you may feel downright paralyzed, but you won't stay there! Soon you will feel more relaxed with the new tasks that are your routine—one day you'll marvel at how you calmly flushed a line while playfully interacting with your child! Getting into new routines gets better rather quickly; what takes more time is allowing yourself the space to work towards an emotionally strong and healthy sense of self again.

Dr. Elizabeth Kubler-Ross has explained the grief cycle many people go through during any large, traumatic change in their lives. The grief cycle can be used to explain what you may feel you are going through. For some this helps to give some structure to the multitude of feelings that they cycle during their child's treatment and recovery.

The very primal emotions of shock, anger, and denial are often the first phases of grief. Many parents are in the first phases of grief during the initial month or two of treatment. Acclimating yourself to the world of a hospital or outpatient clinic can be something you go through feeling like a deer caught in the headlights. Many days you may think there has been a mistake, this just can't be happening. Your fears often have to be hidden as you watch your child receive treatment. You may feel like you are an actress, or cheerleader, even though your insides are in a panic! You learn to flush lines, give shots, change dressings, and collect urine, all during this phase when you may be feeling shock, anger and denial.

The sadness of watching your strong, well-developed, healthy child transform into a frail, thin, sickly child understandably can cause you to feel powerful emotion. You may feel shock again when hair falls out in clumps on the pillow and you suddenly have a bald child. It is then hard to deny that you have a child with cancer. Teens seem to get much more nauseous during chemotherapy. The nausea often can't be controlled and rapid weight loss can affect self-image. You may find yourself mourning this transformation, and yet you have to be the one to stay strong and upbeat for them.

You may feel, at first, that you live in a phase of angry, numb disbelief. Be comforted in knowing this phase will pass and you will feel better!

Your communications with those closest to you can be volatile. There may be misunderstandings and differences of opinion between spouses, as it is difficult to think clearly and logically, especially during the initial phase of treatment, when you spend hours on end by your child's side. You feel exhausted from the monotony of the days and may feel guilty for wanting to escape. But there is no choice but to remain strong. By simply recognizing that these reactions are normal you are taking the first step towards managing feelings that may be very unlike any you've ever experienced. Try to quickly resolve miscommunications with loved ones. It is ok to simply chalk disputes up to the situation at hand, and then lovingly move on.

Sometime during the initial phase of treatment, most people begin to settle into a new "normal" routine. You may find support groups online, at the hospital, or in your community. You may have established a website that gives you strength and support through messages people leave. Siblings settle in to a new routine. Everyone starts learning new roles and you have new hope that the chemicals dripping into your child are doing their job.

Ironically, as things get more routine, many parents find themselves feeling even more depressed. It's as though the initial adrenaline that you lived on as you started treatment is gone. You may find yourself making new "ifs and thens" about what you'll do differently if your child survives. You have a lot of time to think and reflect on where you have come from and where your life is heading. As you realize that treatment isn't quick, that healing takes time, you can find yourself feeling very flat and down.

Take advantage of the resources that are offered to you. Seek out the help this new routine is affording you. For parents who go from full time working parent to full time caretaker parent, there are many, many hours of downtime to fill. Use that time to invest in your own mental strength. Many parents have found that journaling, exercising, baking, knitting, or seeking support groups become ways to cope with the often flat feeling that accompanies hours and days of caretaking.

Depression can spiral up and down as you navigate through your child's treatment. Some feelings of depression are a normal phase of the grief cycle. The degree to which you, your children, and your spouse experience depression is important to monitor. Often it is a sibling, or the spouse who isn't the primary caretaker, who experiences depression first. Don't be afraid to talk to your child's doctor and your social worker if you, your spouse or any one of your children is feeling inordinately depressed. They will guide you to the right place to get help. Remember it is important to take care of yourself so that you can have the reserves needed to provide nurturing support and care.

Your child may have times during treatment where he or she is listless or just wants to quit. Often the drugs a child must take can exacerbate these feelings. If your child can find ways to express his/her feelings through art, music, writing or talking it may help. Trying to bring friends and siblings into the routine as often as possible helps you and your child cope.

Don't be surprised if your child takes on a more "controlling" personality. Children can get very specific about sizes, shapes, flavors, colors of EVERYTHING related to treatment, and may have temper tantrums over things that would not have bothered them before. This is normal. They are seeking to control a situation that they don't have a lot of say in! Try to be patient, but firm. Remember that when your child recovers you don't want to have a child who believes he or she will always get his or her way! It is a fine line, but one most parents have had to deal with on some level. Be mindful of the balance.

Older children may need more sophisticated outlets to avoid feelings of sadness and depression. Having a blog or website, arranging visits from friends during treatment, keeping in touch through cell phones and email, and keeping up with the latest video games are often the most significant

ways to help an older child cope. Each situation is so unique, it is a good time to really communicate with your older child and find out what makes him or her feel best, so you can work to create environments that support their needs.

Don't assume you know what your older child needs—they will surprise you! The isolation of treatment and loss of identity is a major challenge for many older children. Some may not want to become part of the clinic community, instead choosing to get in and out and gravitating more towards their family and friends away from treatment. Watch for signs of depression if teens are isolated for long periods away from their normal world. As with the younger children, there is very little over which older children have control, yet they are at an age when independence is important. You will understandably be protective, but try to let your teen be in charge as much as possible and do as many normal things as he or she is able.

At some time during your child's illness there generally comes a point of *acceptance*. This, too, is a phase of the grief cycle, but acceptance is different than getting in to a routine. Eventually you have a resolve about what your life is now. You pick up the pieces and try to establish new family dynamics. You try to accept that you are going through this experience called *cancer* with your child. You may get to this point of acceptance during treatment, or after your child has completed treatment.

Accepting that your life is in some way back to a new normal is a very fine line. You may be afraid to plan long term. You may be fearful of every ache and pain. You may even be afraid to discipline your child as you would your other children. Acceptance is not resignation. Resignation means staying stuck in the place of grief, without looking for ways to move forward and grow. Acceptance means you have had time to take in change and set new goals and benchmarks for you and your child. You have fear, but with a new wisdom. You know the reality of what you have been through, and yet you move forward.

Don't have unrealistic expectations about jumping back into being the person you were before your child was diagnosed. For many this experience becomes a catalyst for life change that can bring a new sense of purpose and priority. Your child will have wisdom beyond his/her years. Your other children will have the ability to be more compassionate, more aware. The friendships you keep will be the ones that are real. You won't ever be able to take the diagnosis away, but you will have found strength when you thought you had none; courage when fear burned inside; acceptance of challenges that once seemed insurmountable; and hope and joy in every day. You and your child are going through the unimaginable together, and yet the sun rises and a new day comes with the promise of more tomorrows.

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