



Parent Tips

Dealing with the unexpected

Every child responds differently to treatment, so planning ahead as much as possible allows you to feel better prepared for unexpected challenges. It helps to keep a suitcase packed for emergencies and routine hospitalizations. A favorite stuffed animal or blanket to comfort your child can ease the stress of a late night trip to the ER. Keep your medical journal up-to-date with all the medications your child has received and any side effects. This will avoid confusion in case of an emergency.

It can also help to talk to other families whose child has had a similar diagnosis. Join our Closed Facebook Parents Group or call us to be connected to another family.

"It's a good idea to pack a bag for both you and your child and keep it ready and in the car. If you have to go to the hospital unexpectedly, the last thing you will want to do is pack."

"When our daughter's counts were low and they took her off treatment for the first time, we were horrified. We thought it meant things weren't going well. We later learned that all of the kids go off treatment for low counts at times and that just means that the chemo is working. By taking the kids off chemo when their counts are low, they are ensuring that the kids don't get more chemo than their bodies can handle."

"At first we tried to figure out the meaning of the fluctuations in our daughter's counts. Over time we realized that all of the counts go up and down and that is what is supposed to happen while the child is on chemo."

"It's wonderful when family is supportive, but don't be devastated if they are not. Everyone copes with stress differently. Just try not to take it personally. We had some family members who, even now after a year of treatment, have not inquired about our daughter. Instead of dwelling on it, we just say to ourselves, they can't cope and we have to accept that. It's not easy to do, but it requires less energy than staying upset!"

“Very few, if any, of your family and friends will understand how difficult and long the treatment is. Some of the people you know will be very supportive but others may just disappear from your life because they do not know how to handle it. A lot of people thought it was a short course of treatment and we were done. They had no idea what was really involved. It is easy to feel angry and hurt by all of the people in your life who don’t understand what you are going through. We all have. Try to let it go and focus on those that are supportive and want to help. We have met some wonderful people and have become even closer to our family and friends.”

Unexpected gifts

“How strong my little daughter is—yes, she has a life threatening illness. Yes, she has to endure treatments that I would not wish on my worst enemy. But she is so full of life and laughter and enthusiasm that my heart is filled with awe and I am humbled. If she is able to be strong enough to deal with this, so can me.”

“Our son played travel soccer during his last year on maintenance. He still had his port in and was a bit behind on his foot-work but it was a great season.”

“My husband and I are closer now and even happier than before this happened. I can’t believe that one myself.”

“One unexpected gift I have received in this ordeal is the realization of the kindness of others. I have been amazed at the concern and compassion complete strangers have shown when they discover what my daughter is going through.”

“My son is so responsible and mature, kind and empathetic. This horrible thing has helped to shape him into an amazing person.”