

Living with low blood counts

Your child will be immune-supressed at many times during treatment. Keeping them safe from viruses and germs will be an important factor in their treament. Basic handwashing and avoiding crowds are your best first line of defense.

"Though all of our friends and relatives were aware of the need to limit James exposure to germs, I was shocked on several occasions that people (even folks with medical experience who should have known better!) would visit with a sniffling child or worse. I became less bashful about cutting short such get togethers and being very clear about James' vulnerability. At his nursery school, the nurse also made clear that sick schoolmates were a threat to everyone, especially an immune-suppressed student. His school was vigilant about returning sicklings home, where they belonged, and I still appreciate that!"

"Never feel embarrassed about the measures you have to take to keep your child healthy. Some friends may have been offended when I left a play date because their child had suspicious drainage from their nose – or worse! But I would always wait a day (until I wasn't so upset!) and call and explain – AGAIN – that our daughter could not be exposed to common childhood illness if at all possible. Remember that the other parents haven't walked in your shoes. Your goal is to help your child and sometimes that means taking the time and effort to educate the other parents whose children are important to your child. Our kids deserve to play and have fun too!"

"Make sure school knows to tell you if there are any cases of chicken pox or flu so you can keep your child home. Those can be really hard for immune-suppressed kids."

Things you CAN do when their counts are low

"After many weeks at home, we found some fun things to do to pass the time. Sometimes we would have the whole family camp out in the living room, we had picnics on the porch. She learned to cook, plant seeds, and do crafts."

"We did 'at home spa days' with homemade facial masks, manicures and pedicures!"

"There were many times when our daughter wanted to go out but could not because her counts were too low. One thing she really enjoyed was shopping online. Some of her friends gave her gift cards to stores and she could use them online. She had fun ordering the stuff and then would look forward to it coming in the mail."

"Outside became our great escape. When our 3 ½ year old daughter was really ill from induction, it was springtime. I purchased a heavy duty 3-wheeled stroller and would just bundle her up and walk her up and down our wooded lot and show her all of the signs of spring arriving. It inspired me and I hope that it inspired her weary soul in some way."

"We went bird watching. There is an eagle watch in February and great birds in the spring, summer and fall. We even got our son's teacher to come with us one summer day."

"We took our son fishing to an isolated spot on a lake. I baited the hook and took off the fish. He loved it just the same. In fact he used to laugh as I tried to put the worm on the hook and remove the fish with chemo gloves on while grimacing the entire time. We have lots of great fish pictures. No hair but fish...."

"Go to the drive-in. Take short walks. We learned to play chess! Reading a book together gave us something to look forward to at the end of the day." We also shared books on tape for long drive to and from the clinic."

"Sometimes on Sundays we would go to my husband's office when no one was there just for a change of scenery."

"We would schedule a play date with someone who was healthy during the "quiet times" at local parks, beaches, etc. when we were sure we would be the only ones there. It was great to get outside and we always felt more comfortable playing with kids—even healthy ones—in the fresh air, as opposed to stuffy houses."