

Stories from Parents:

Parenting a "cfer" and a non-cfer

Our child with cystic fibrosis is our oldest. We made a conscious decision to wait and see before we had more. We decided, after much consideration, to have a second child. He came along 7 years later. We went into it not knowing if he too was going to have CF. He does not.

By the time we decided to go ahead and add to our family our daughter had already been hospitalized 3 times and had home IVs as well. This way, we believed, we knew what we were getting into. Since his birth she has had more hospitalizations as well as home IVs. Both of these scenarios, as well as everyday living with CF, can present some challenges for parenting the non-cfer. There are a lot of emotions involved for the "healthy" sibling. Early on in our daughter's life we decided she would live a life as close to normal as possible. We have to make as much of an effort for her brother. It takes a lot of balance and dedication.

We have always parented both children as individuals. We developed some guidelines in our house that seem to help. When our child is hospitalized one of us is always with her and the other is with our son. We try to spend family time for just the 4 of us in the hospital. We also use Skype and AIM video chat to keep us all close. Making sure both children feel loved and acknowledge that sacrifices are being made is important. We don't dwell on the negative but we do allow honest conversation.

We have always been big on communication. We are very open with both of the children's school community. Sometimes my son would put a brave face on at home and feel the need to express his true feelings at school. He was able to do that since we were all on the same page. The school always knows what is going on so nothing he says is unexpected. We have also started using counseling services for both children. Again, this is another outlet for them to express their concerns and fears in a safe environment.

I have found at times my son is jealous of the attention that his sister gets. I have also found he is extremely empathetic. He is keenly aware of the needs of others.

Some things to consider: know who you are as a family, know what your schedule is like when your child is well and when he is sick, and know that it is possible to parent both a "sick" and a "well" child.