Explaining Lupus to Kids

by BARBARA LEECH

Kid-Friendly Ways to Explain Lupus

I am many things, and of my many roles the most important to my heart is being a mother. I have four children, two grown and two under the age of eight. And as a mother battling a disease that many do not understand, explaining what lupus is and is not to them has been a big challenge for me.

When I was officially diagnosed, my two youngest children were toddlers, so there was not much in way of an explanation required yet. My two oldest were teens and immediately became overly concerned, googled it, saw that it can be deadly and went into “mom is going to die” panic mode.

I handled that as best as I could have, but I simply said that many, many people survive this battle, and though there may be times of hospitals and ER visits, it does not mean I am succumbing to this disease. In the end, I basically made a pact that I would not hide anything serious that was happening and if things were getting scary, they would be the first to know.

And I think that is a huge part of what older kids need. They need to know things are really okay until they are most certainly not. They need to be able to trust that I will be there for their weddings, their children and the future. They don’t want surprises with this battle. So that was our agreement.

My younger children are now 6 and 7.5 years old. They are now old enough to ask questions; they want to know what lupus is, why I have bad days and what it feels like. They too want to know I won’t die.

Here is how I got about explaining lupus to kids:

“Everybody has sort of an army of 'antibodies' in their body whose mission is to battle bad invaders. These antibodies are supposed to fight off sickness (and germs), heal boo-boos and disease and protect their home base, the human body.

Mommy’s army has gotten crazy and confused about their mission though. They think things like my lungs, my heart and joints (every spot mommy can bend) are invaders and don’t belong there. They only go out on a mission to attack invaders when they get really excited though. Some days they are calm and don’t try to battle anybody so mommy feels good. But other times something gets them riled up and confused. Then I have to take it easy to get them to calm down.”

There are key points for children to realize too. Those pesky thoughts they may not ask about or express:

- This is nobody’s fault, not yours, not mine. Everybody has their own challenges in life and this is mommy’s challenge. And mommy is a tough cookie!
- Lupus cannot be caught like a cold.
- Lupus is not cancer, even if I undergo chemotherapy lupus treatment, it is because it quiets the army, not because I have cancer as well.

- Lupus can make mommy tired, move slower than normal, feel cranky, see many doctors and have to say no to certain activities. It does not mean we won’t do them, just not right now.

My children seem to know when I am having a bad day and that is when they ask the most questions. I am glad that they do and welcome them.

I think dialogue is so important in keeping fear at bay which is why explaining lupus to kids is so important. Illness can scare kids and even tear a family apart, but not if there is communication, patience and love. I want them to feel as safe and secure about my condition as possible.

I try and think before I answer, so I know how my words might be interpreted by them. They are not adults and it is not easy to navigate these waters, but it is so important to make them a part of my journey.