

SAYING THE ‘H’ WORD

Struggling to Say Hepatitis Out Loud

A Parent’s Perspective

Telling a Child for the First Time

By Christine K.

Since our daughter entered our lives seven years ago, her hepatitis has been a veiled secret from her. My husband and I talked about it. We talked about it with doctors and we talked about it with close friends, but we have never talked about it with her.

When she was a toddler, we began talking about the need for precautions, how blood can carry viruses and how we should never touch anyone’s blood, or let anyone except a parent, teacher or nurse touch our own blood. We said all the right words that can be spoken safely to almost anyone.

Now she is almost 8 years old. It is time to say the “H” word out loud to her.

Our daughter is adopted. She grieves the birthparents who made an adoption plan for her instead of “keeping her.” Her understanding of the events that led to her adoption and her life in the United States are becoming more sophisticated, as is her anger.

I marvel at all she has had to understand and assimilate at her young age, and the last thing I want to do is add more weight to her legacy of loss. The last thing I want to do is acknowledge to her and myself that I am powerless to stop this disease. The last thing I want to do is acknowledge she may die before I do.

If I could, I would keep this word from her forever. But I can’t. I won’t trade her trust in me for the comfort of my silence.

So the clock ticks, her eighth birthday, her eighth physical exam with the inevitable blood draw, approaches. The pact I have made with myself is to sit her down and in the most age-appropriate way I can muster to explain about viruses in her bloodstream. I will explain how they can settle in her liver and damage it and why the doctor must

draw blood each year to make sure the viruses are not hurting her.

And then, I have to tell her to do something else that I have never told her to do before. I'll have to tell her to keep this a secret. I'll have to explain how private information should not be shared. She will perceive that this new thing about her is somehow bad because it cannot be shared.

I'm groaning inwardly as I write this. I dislike secrets, but I have been immersed in one since her diagnosis. Now I will draw her too inside this veil.

She will see the fear in my eyes. She will see me staying calm and measured, but when I hold her she will feel my heart racing, like a wild animal trying to outrun its shadow.

In this discussion, and in the ones that will follow in the years ahead, I will assure her that her father and I are her ever-present partners in this journey. I will assure her we will be there, always in the wings, as she gets older and charts her own course. But my unspoken prayer is that she reaches her destination long, long after I reach mine.

My hope, like every parent's hope, is that she'll finish her journey with her children and grandchildren beside her, decades after I have slipped over the horizon.

But that is not what I will tell her when I say hepatitis out loud to her for the first time. Instead, I will try to explain about viruses and how they don't have to haunt your dreams. I will try to tell her they are simply part of life's journey, a legacy to live with and learn from.