

Donna Bryson

Asthma

"My daughter had a great doctor with a great nurse. Involving the patient and caregiver as active participants is key." I am a wife, mom, friend, nurse, asthma educator for the American Lung Association, and I have severe persistent asthma. I was diagnosed nearly 60 years ago, and my earliest memories revolve around asthma: doctors, hospitals, oxygen tents, painful treatments, and that memory of struggling to breathe and the fear of that next time.

In high school, one of my dearest friends, Patti, who also had severe asthma, was found on the floor dead with her inhaler clutched in her hand. Until that moment, I believed the lie that was my mother's prayer: children don't die from asthma.

Then my asthma attack came. It was so swift that it didn't matter how hard I fought. I felt my lungs turn to stone, and air only moved in and out of my throat. I couldn't speak, or say "I love you" one last time. As the world closed in, became a cold gray cylinder, and finally a black speck, the last words I remember hearing were, "let's tube her."

I woke up, I got better, and my life with asthma went on.

Asthma continued to shape our lives. My son was two when he was hospitalized the first time with asthma. I sat by his bed and watched him endure the same things that I endured. I knew it was my fault and that I had done this to him—he had my asthma. I knew what life had in store for him, and my heart ached.

My oldest daughter also had asthma, which worsened in middle school. She was very athletic and played hi-intensity sports like basketball, soccer, and fast-pitch softball, so she was given a compact nebulizer. She was able to take Albuterol nebulizer treatments on the field or court. But when you need special treatment, it makes you different, which you do not want in middle and high school. She was very reluctant to come to the sidelines because she worried that it would be perceived as a "cop out" if she had to leave the game. I had to intervene and advocate for my daughter.

ASTHMA

Asthma is a chronic disease that swells the airways, or breathing tubes, of your lungs. This swelling (inflammation) causes the airways to make thick, sticky secretions called mucus, and it causes the muscles in and around your airways to get very tight or constrict, which makes it very hard for you to get air into and out of your lungs.

Asthma can be caused by genetics, allergies, respiratory infections, and irritants such as:

- · Molds and dust
- · Exhaust fumes from vehicles
- · Chemicals in garden sprays
- Strong odors from paint, perfumes, colognes, hair spray, deodorants, and cleaning products
- · Tobacco smoke
- · Weather changes
- · Stress or exercise
- Medications
- Sulfites in foods such as dried fruits, wine, and beer

Learn more: ATS Patient Information Series. "What is Asthma?" New York, NY: American Thoracic Society, 2013. patients.thoracic.org

2 Donna Bryson

Also difficult was convincing the school that she must be allowed to carry her inhaler. Thank goodness that all 50 states now have self-carry laws, although the implementation of those laws may still need attention.

When the NIH Heart, Lung, and Blood Institute Guidelines appeared in 1989, and the use of inhaled corticosteroids was recommended, my world changed. My children and I improved dramatically. We still had exacerbations, but they were fewer and less severe.

When my third child was born, the medications were better and our understanding of the disease was improving. Her pediatric pulmonologist wasn't afraid to treat her with increased amounts of inhaled corticosteroids that she required for control. A nurse and I sat down and together, developed her first Asthma Action Plan, and discussed what I needed to know, why, and how to use the plan. Needless to say my daughter had a great doctor with a great nurse. Involving the patient and caregiver as active participants is key.

As my daughter got older and her care plan was updated, she was the one involved in decisions about her care and management of her health.

A school nurse introduced me to Open Airways for Schools, which teaches children about their asthma symptoms, medication, triggers, and warning signs, and gives them a chance to talk about how they feel. For the past 14 years, I have been working for the ALA, and I have had the opportunity to teach asthma self management. As a result, my confidence and skills in managing my asthma and my children's have grown tremendously.

Donna Bryson was a patient speaker at the ATS 2014 International Conference in San Diego.