

A Parent's Perspective on Strabismus Surgery

By Kelly Warnick

My son, Matthew, was diagnosed with strabismus at a young age and what a journey it has been. At first, I was very overwhelmed, knowing so little about the condition. But over the years, our family has learned and grown with Matthew through the physical and emotional challenges he has faced with strabismus. Over time, Matthew has emerged confident, thriving and with a great sense for the importance of his eyes and why he must protect them.

Matthew's Diagnosis and Treatment.

Matthew was diagnosed with strabismus at 17 months of age. At a routine check-up, Matthew's pediatrician noticed that his left eye was turning slightly inward and referred Matthew to a pediatric ophthalmologist for a more detailed examination. This exam confirmed that Matthew had a form of strabismus, esotropia, where one or both of his eyes would turn inward intermittently. When I received the diagnosis, I was very overwhelmed. I began to research the condition and learned how strabismus can alter how a person sees the world. What was my child seeing or not seeing? Was he growing up with a perspective of the world very different from mine and did he know any different? With Matthew being so young, he could not explain to me what he was experiencing.

Matthew's pediatric ophthalmologist treated him with bifocal glasses. It was a challenge, given Matthew's young age, to teach Matthew to consistently wear his glasses. Many days I would find his glasses lying on the floor while Matthew was running off into the next room for his next adventure. After much perseverance particularly from Matthew's big brother, Matthew began to wear his glasses steadily

and the next challenge was teaching him to use his bifocal. Soon that became second nature for him as well. Matthew's eyeglasses effectively controlled his strabismus for many years.

Matthew's Feelings in Growing Up with Strabismus

Once we cleared the hurdle of getting Matthew into glasses and on a stable course of treatment, we faced some emotional challenges as well. As Matthew became older and more aware, he began to feel different from his peers because of his glasses. For many years, he was the only child with glasses in his class. Many of his peers would ask him why he wore glasses and some would even grab at them out of curiosity. Still others would ask why his glasses were "cracked" (referring to the bifocal line). Matthew would get frustrated and not want to wear his glasses. This just tugged at my heart, but I always came back to the realization of how crucial it was for Matthew to continue to wear his glasses. If untreated, strabismus could jeopardize his vision.

As I eventually found with Matthew, if you can explain things to your child so he understands how important it is to keep his eyes healthy and strong, you will make great strides in helping him emotionally as well. With Matthew, we told him that he was his eyes' greatest protector and that his glasses were making his eyes as strong as they could be. I soon learned that he was explaining this to his friends in his own words and, since then, there have been very few questions or comments by his peers. In fact, one child (after speaking with Matthew) told his mother that he needed an eye exam because he needed to make sure he kept his eyes strong. There will always be kids who tease, but what Matthew and I found was that many of the children who were making comments were simply curious and just wanted to understand. Once he explained it to them in his own way, they accepted it and moved on.

What also has made a tremendous difference for Matthew is having him connect with someone who likewise has strabismus and who can understand what Matthew is feeling both physically and emotionally. Matthew's friend was diagnosed with strabismus at a very young age and has dealt with it

for several years. He has been such a source of encouragement for Matthew. They have talked about how tough it is to be the only kid in glasses. They have talked about how they both do not like the eye drops during their routine checks at the ophthalmologist. Yet Matthew's friend always reminds him how important it is to do everything he can to keep his eyes strong and healthy.

There is such a benefit to parents connecting with others as well. I have been so fortunate to have found an incredible support system of medical professionals and friends. They all have taught me so much about strabismus and how to help and encourage your child while dealing with the condition.

Increasing Signs That Matthew Needed Eye Muscle Surgery

For several years, Matthew's eyes were stable through his glasses. However, as Matthew was approaching five years of age, his glasses started to become less effective and we began to see a change in his condition. Matthew's eyes would turn inward intermittently even with his glasses. He began to have balance issues. His depth perception was not developing. He found it challenging to focus closely on things which affected his fine motor skills. Even his letter writing, which is so important in Kindergarten, was quite a task for him. Ultimately, the challenges with his vision began to affect his self-confidence. He became frustrated with certain activities and started to withdraw from doing them. Having exhausted all the non-surgical treatment options for his strabismus, we began to look at whether the signs were sufficient to consider strabismus surgery.

Making the Decision To Go Forward With Surgery

No parent wants to put their child through a surgery. Yet all of the signs were pointing toward it. My husband and I were faced with a tough decision whether we should proceed with an eye muscle surgery for our child. I highly encourage anyone faced with a similar decision to sit down with your child's ophthalmologist and ask the questions you need answered in order for you to make an informed decision. Ask about the risks of surgery, the surgery itself, how your doctor thinks the surgery will help your child,

and what you should expect to see with your child as he/she heals. Our doctor was wonderful in taking time to answer all of our questions. This helped us immensely in feeling comfortable about our decision. If you are still unsure whether you are making the right decision after speaking with your doctor, get a second opinion from another medical professional. It can only help in your decision-making process.

A recurring question of ours in considering surgery was this: Can we really put Matthew through a surgery, given his young age? And yet, in speaking with our doctor, we began to realize two things. First, once there is an indication for surgery, there is no advantage to waiting. The younger the child, the more flexible and adaptable is their neurology. Second, the older the child is the more aware he/she is of the concept of surgery and the more anxious the child can be. We found both of these points to be very compelling when we were weighing our decision to go forward with surgery.

Explaining To Matthew about the Upcoming Surgery

At a younger age, Matthew might not have understood to be anxious about the surgery. But at age five, he was very worried. It helped to reassure him that he was in good hands with his doctor and how much the surgery would help him. It also helped tremendously when Matthew connected with a person who had undergone the same type of surgery and had done very well with it. He offered Matthew such encouragement about the surgery and really rooted him on. After this, we began to see Matthew start to relax about the surgery.

Many hospitals give tours of the pediatric surgical unit prior to a patient's surgery and Matthew had a very positive experience with this. The medical professionals related so well to him and helped to relieve a lot of his anxiety simply by showing him what to expect (on a very basic level) and how comforting an environment it was in the unit. It was also very helpful for Matthew to hear from them what he might be experiencing after the surgery and how these post-surgical side effects should pass

overtime. Indeed, Matthew learned he would have “red eyes” post-surgically and also could experience some double vision. Upon experiencing this after the surgery, it was very reassuring to him to remember what he had been told – that these symptoms should go away in time and that he did not have to worry about it.

Matthew’s Growing Confidence and Newfound Abilities

Matthew has benefitted dramatically from the eye muscle surgery. We now look back on our decision and know it was the right course of action for Matthew. Matthew’s depth perception is finally developing. His balance has improved significantly. He now enjoys activities that require him to focus on things close up. His fine motors skills are coming along nicely as is his letter writing which presented such a problem in the past. His confidence is soaring and his social interaction is strong. He still has a need for bifocal glasses, but he has an increased respect for them given all he can do while wearing them. I was so touched recently when he brought home his writing journal from school. On one of the pages he had written about his eyes and how proud he was of them.

It has been quite a journey with Matthew and his strabismus. Occasionally, I look at his first pair of eyeglasses and think how far we have come. Now, his glasses are truly a part of him and they give so much to him. I never tire of seeing the pride on his face as he discovers new abilities resulting from his growing depth perception. He is thriving. If there is one piece of advice that I could pass on to parents faced with similar situations, it would be this: Have trust in your doctor and your doctor’s medical team, be patient and knowledgeable in figuring out the best way to treat your child’s condition, connect with others and have faith that you and your child will work through it together and be stronger for it.

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