

Preparing Your Child For Surgery

By Sarah Joy Smith



Reagan-David the morning of his open heart surgery

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I believe we go through valleys and learn more than we could have if we had remained on the mountaintop. I also know when we learn these things it isn't just for us to keep to ourselves but to share with those around us. We do not believe our son and family has gone through the medical journey we have faced for nothing and we desire for others to find hope and encouragement through all that we have learned.

Choose the right time to tell them they need an operation. It is helpful have to think through how your child might react to the news of surgery and consider the age. When our two-year-old had surgery we didn't tell him until that morning; at age five he need surgery again and we also waited until the morning of to tell him. We knew that after seeing his brother go through open-heart surgery, we would instantly instill fear in him if he knew too far ahead. We chose to wait. When it came to Reagan's open-heart surgery (OHS) we told him the day we found out because the next morning we were meeting with the surgical team. We had no choice.

We also were careful with the time of day that we told Reagan. We chose afterschool because we knew bedtime was not an option for our emotional boy. All my kids are too tired at bedtime; which makes them super emotional. Bedtime was going to be hard enough the day we told him, it was better to give him the chance to process the news before getting in bed in a dark room. Some children might be best first thing in the morning; some may be bedtime. Only you know your child.

Choose your words carefully. The first thing I can say is to ask God for wisdom to talk to your child on their level. I was pretty vague in my first explanation to Reagan, it went something like this, "Reagan, remember how the doctor said we could go back in six months? Well, he was wrong and he wants to make sure your heart is okay so we are meeting with the

doctors who will perform surgery on you to fix your heart." There were instant tears followed by a series of questions. I only gave basic information in that first sentence or two and I let him choose what he wanted to know from there. I never used the term 'open heart' or told him he would have his heart stopped and be placed on bypass; those are all things that cause fear in us. I also made sure everyone around him chose their words carefully. Over the next ten days we had to answer a lot of questions and sometimes the same ones in different ways until he got the information he was searching for. Children will surprise you that they don't need nearly as much information as we would think they would want.

Give them time each day to sit with you and be calm/ still. We practiced deep breathing when Reagan *wasn't* panicking for two reasons.

1. It helped him stay calm by making it a habit.
2. It helped him to rest.

Deep breathing allows us to control our heart rate. If we can learn this practice when we aren't upset or in a panic, we will be able to use it when we are to bring down our heart rate and come back into a calm place. The Bible is clear that when God made us he breathed life into us, our breath is so important. We breathe in through our nose and out through our mouth and call them breathing prayers. As we inhale, we say a short prayer or the name of Jesus and as we exhale, we finish the prayer.

Example of a breathing prayer:

Inhale - Jesus you are with me,
Exhale - You will never let me go.

Our faith is incredibly important to us and this was a good time to sit and listen for God to speak comfort to us. There were many times that Reagan would be brought to tears because he said he could feel God's love for him as he sat there breathing deep.

Memorize a scripture or create a small phrase that points them to their faith. This was the best thing we did with Reagan as we waited for surgery. Reagan's phrase was based on a Psalm that my cousin said between the age of 2-4, as she battled cancer. I gave Reagan the Psalm and we re-wrote it

together to fit his circumstances.

“Whenever I am afraid, I will trust in You. In God I have put my trust; I will not fear.” Psalm 56:3-4

Reagan’s translation “In my heart surgery, I choose to trust Jesus.”

Reagan often said this verse several times in a row or until he fell asleep at night.

Give them the chance to visit the hospital and meet the doctors ahead of time. We met with our surgeons and before they met him, I asked the nurse to make sure they spoke to Reagan and not like he wasn’t there. I also asked them to not go into great detail or use the ‘open” word. Unfortunately, this message did not get to them and because he was in the room with me the head surgeon thought I had said it was okay for Reagan to know the details of his surgery. He began to tell me about what they would do, and it only took one sentence and Reagan was ready to throw up. The surgeons both felt awful and they immediately stopped and got a nurse to escort Reagan to my mom who was in the waiting room.

We also gave Reagan the chance to ask questions to the doctors and nurses. It sometimes surprised me at what he was worried about, like if they had cheeseburgers and French fries. But then as the days got closer, he wanted to know how many tubes he would have when he woke up and how many IV’s would be there and where they would be. He would write down his questions so when I would talk to a doctor on the phone or we would go to the doctor we always knew what needed to be asked.

Meet your Child Life Specialist; they will be your guardian angel. All children’s hospitals have some type of Child Life Specialist, but they sometimes have different titles. These wonderful people are trained to make kids happy! They are there to calm them and play with them and they make every hospital stay so much better than if you did not have a CLS. Our CLS took us on a long tour of every room Reagan would be in except the operating room. She was amazing as she guided Reagan through that CICU room and showed him all the machines and told him about the tubes and contraptions he might encounter. This truly helped Reagan to feel some

sense of control as he prepared for surgery.

Exercise. If they are physically able and cleared by their doctor, I strongly encourage thirty minutes of daily exercise as you wait. This not only builds the immune system but it gives them a sense of empowerment and control over their body. We walked and/or ran each day on top of his normal play like baseball and basketball in the neighborhood.

Have play-dates. I was fearful of germs as we waited, and I had my household washing hands like crazy and taking vitamins. It was tempting to keep him home so germs couldn’t get to us because I was afraid he would get sick or I would and then I would not be able to be in that room with him. The bottom line is kids still need to live a normal life. Our fears are ours not theirs, let them live. It was important for Reagan to have his BFF spend the night at some point before surgery. He knew he would have a long a recovery and may not be able to really play with him for a while, so he wanted time to play before surgery. We made this a priority.

Keep your routine and discipline the same. Keeping your routine is good for your child as you prepare. They need to know that they are still expected to do the same things as always and that their behavior can still have consequences. Discipline can be the last thing you are worrying about when as a parent your biggest concern is if your child is going to survive the surgery they are facing. Reagan is a very emotional child to begin with and we have to really help him in this area, add to that all the fears and anxiety of surgery and we had a true beast on our hands at moments. We still made him sleep in his bed even when he was sobbing and ready to throw up, we just rested on the edge of it or on the floor until he settled down. The last night he slept with us and trust me, it was more because I was so scared of losing him the next day during his surgery and my need to be near him.

Ask them what they want to take to the hospital with them. I let Reagan make a list of what he wanted to pack for the week he would be there. A week is a long time for a kid to be gone from all that is familiar to them so let them bring along their choice of comfort items. Reagan’s list looked like this:

Drawing book and pens
Pillow
Slippers
4 Lego people
Books
Robe
Kindle
Baseball cards
Magazines
IPad
Ipod
3 or 4 matchbox cars

Pretty important stuff to a nine-year-old.

Teach them to pray and lead them to Jesus. This would be the most important thing as we prepared Reagan for the road ahead. I can't stress enough what a difference it made to make him pray for himself and his fears. At first, he didn't want to pray out loud, he has never been a kid who likes to lead prayers at the table or bedtime, but we have always made him take his turn. Now more than ever he needed to make this battle in his mind for fear or peace his own. Only he could turn off the fear through Christ's love that casts out all fear and choose to walk in peace. The first step was getting Reagan to recognize the fear and that when that emotion started it meant it was time to turn to Jesus and ask for his peace to replace that fear. This was an incredible time to teach Reagan these foundational aspects of his faith and make it his own.



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