Getting ready for aortic surgery

kids/teen edition
When you first learn you need to have aortic root (heart) surgery, it can be scary and you may have a lot of questions. So, we asked some of our favorite kids and teens about their experience to give you advice about what it is like. Everyone’s experience is different, but we hope this helps you to prepare and to ask questions of your doctors and nurses.

There are some pictures of blood and tubes coming out of the body (normal parts of surgery!). We just want to give you a heads up!

Thank you to Caslin for all the photos her family took throughout her hospital stay. And thanks to all our LDSF friends for giving advice and contributing, including:

Aaron  Jessica
Miles   Courtney
Gabi    Logan
When the Doctor told me I needed surgery, I ....

- wasn’t worried because my doctors were good doctors
- was very scared
- was not nervous because I knew that at some point I would need it
- was terribly upset, especially having just had another aortic surgery a year before. I remembered the pain and feeling helpless
- was nervous and scared
I asked a lot of questions of my family and doctors

- How long would I be in the hospital?
- What were the risks?
- Would I need to take blood pressure medicine after? Would I still have the same limitations on exercises?
- Will I be OK? When will I be extubated?* Will we really go back home?
- Will it hurt? What exactly will you do? How long will I be in the hospital? How long will it take to recover? Will it leave a big scar? Will I be able to do normal things after the surgery? What restrictions will I have post-op? Will I have to ever have this surgery again or will it completely fix the problem?

*During surgery, a tube is place down your throat to help you breathe. The tube is removed sometime after surgery and during recovery. This is a normal part of surgery.
What was it like telling your friends you needed surgery?

- It was normal for me but scarier for them.
- I tried to show them it was all going to be okay and not to worry.
- It wasn't that hard because they knew I was going to have to have it at some point.
- I had just recently done a presentation on Loeys-Dietz syndrome to my entire class (in 6th grade), including telling them how it affected me and answering their questions. I didn't really talk about specific surgeries with my school friends, only with a couple of my closer friends. I didn't get into the details.
- Not so bad. I am close to my friends so they were nervous and scared for me but they did all they could to try to understand and really be there for me.
How old were you when you needed surgery?

- 14
- 2
- 13
- First time I was 4, second time I was 12, third time, I was 13
- 14
How did you describe aortic root surgery to your friends?

- I said that they take part of my heart out and replace it with plastic

- They put a neoprene sleeve over the aortic root to prevent it from dissecting

- I didn't. They don't need to know that much

- The first time the doctors put a plastic tube over the aneurysm (the bubble that formed where the artery joins my heart). The second time they cut out the aneurysm, then sewed in the tube

- My mom did a lot of research and had pictures of what they were going to do so it made it a little easier to tell my friends. Basically, they cut you open and hook your body to a bypass machine that will pump blood through your body while they repair your heart. With the root replacement, they remove the aortic root (the part that is dilated) and insert a synthetic sleeve and then attach that to the heart and the aorta. Then they put the heart back inside and sew you up
What is aortic root surgery? (a response from your LDS doctors)

The aorta is the main tube that brings blood from the heart to the rest of the body. It is shaped like a candy-cane. The most common place of enlargement (dilation, aneurysm) is right at the base of the aorta where it enters the heart. If this portion of the aorta gets too big, you may need surgery to replace it. In surgery, they give you drugs to put you to sleep, then they open up your chest to see your heart and aorta. The aortic root is cut out and a synthetic graft (tube of unbreakable fabric) is sewed in to replace it.
Getting ready for surgery. What did you do to get ready for surgery?

- Not that much. I had dinner the night before since you can’t eat much after surgery
- Lived life to the fullest
- I tried to forget about it and not worry about it.
- Since my teachers knew, they coordinated schoolwork for when I was ready to work again
- Mom talked about what all was going to happen and was open and honest about everything. I trusted that my mom wasn't going to let anything bad happen to me! I could see from the huge notebook she had that she had covered every question I could have
What was it like before going back to surgery?

- I was slightly nervous but also excited in a weird way.
- My parents and the nurse kept me talking and laughing so I wouldn't think about it.
- Obviously, I'd generally be anxious and scared. But my parents just stayed with me and the doctors generally let them accompany me all the way to the OR. My mom would always remind me to think of happy thoughts and would share some with me, recalling moments she knew I had loved, like days at the beach, or times with my cousins, or the things we'd do once we returned home, like pizza nights, going to the library, and shopping.
- A little scary, but my family helped distract me by making me laugh.
What did you bring to the hospital with you?

• Blankets, pillows, anything to make me feel more comfortable
• Clothes and my favorite teddy
• My blanket and a stuffed animal. My phone
• First, the essentials: my phone, my iPad, and books. My pillow, toiletries, and underwear, comfy socks, leggings, and button-down shirt to wear when I got to the floor
• Just my phone, clothes, and grooming items. I listened to music a lot on my phone to help distract me and played games on my phone
Who was part of your hospital team and what did they do or how did they help you?

- My surgeon and cardiologist and lots of nurses, some better than others, but mostly good people
- Nurses, Chaplain (pastor or priest), Geneticist
- Sam was a nurse and she made me laugh. Lauren was the nurse in ICU and she made sure I was okay
- Beyond the doctors and nurses, there were the Child Life Specialists, who always came up with fun things to do. I sometimes didn't feel like doing anything, but it was still nice of them to check in
What was it like waking up from surgery?

- I was in a lot of pain and I felt very tired and I could barely move or make out anything anyone said
- Very, very tired and sore
- I can't really remember
- Awful. One of the worse parts for me was always the waking up part. I was unable to communicate and extremely thirsty, but not allowed to drink anything
- Scary. I had three tubes in me. I couldn't swallow because of the breathing tube. My family wasn't there because they couldn't stay in the CICU with me but the nurse called them as soon as I woke up and they came right over. I remember wanting something to drink and pancakes
Tell us about your parents staying with you in the hospital

- They just took turns staying with me and it was pretty normal
- My Mom stayed at the hospital all the time, and my Dad visited every day
- They took turns sleeping on the couch and the reclining chair - not particularly comfortable
- My parents couldn't stay in the CICU, but I was only in there less than 24 hrs. Once they moved me to the step down unit, my mom and uncle were able to stay in the room with me. My uncle stayed one night and then he had to head back to work, but mom stayed the whole time. My older sister and a few of my friends came to visit. I was in the hospital four days and then went home
Who came to see you in the hospital?

- My mom, my older sister, and my favorite uncle were there the day of my surgery. My uncle is a big goofball and he played with me and did things to make me laugh to help ease my mind.
- My friends and family. I liked it, but at the same time I was almost embarrassed that they were seeing me like this, but I knew they didn’t care.
- My three brothers, and an aunt and uncle. We were not in our hometown.
- My aunts and uncles, grandparents, and sister. I never liked having too many visitors in the PICU, just my parents, grandparents, and uncles. Once I was in the room, then others could visit, too, although I always preferred to have non-family visits when I returned home.
- My best friends stopped by and brought me something to eat. I was so happy to see them. Also, my older sister came and brought food for me.
What types of gifts helped you feel good while in the hospital? Who were they from?

- I didn’t really like any of the food anyone sent me. But I did like the gifts that helped me pass the time, like coloring books or using an Xbox or something.
- Balloons, from my family.
- A fan! My dad bought me a fan and that made me so much more comfortable. I also got a board game that I’d been wanting - while I couldn't play it in the hospital, I was super excited to play it after I got out.
- Perhaps the gifts I enjoyed the most while in bed were simply balloons, brightening up my room. I also liked having posters on the wall, the kind of posters in *Tigerbeat* and *American Girl* magazines.
- I got a comic book to look at from my sister's dad and a gift bag full of goodies and snacks from my grandparents. I also got balloons and food from my friend and sister.
What did the nurses want you to do to help recover faster?

• I think that the nurses often pressure people to recover faster than they are comfortable with, but in the end they probably know what’s best
• Blow bubbles
• Sit up, breathe deeply, walk
• Sit up and do physical therapy as soon as I was ready
• They wanted me to get up and move around and also sleep when I could
What made you feel better and what was hard about recovery?

- I just liked laying down and watching something with people
- My sternum (chest wall) did not heal, and I had to have a 2nd operation to fix it
- The hard part was the folly (a tube to help you urinate) and the chest tubes - not fun. Peace and quiet made me feel better
- Pain meds helped, but not entirely
- I felt better when they removed the chest tubes. That was the worst part. It felt like a vacuum cleaner sucking the inside of my chest. Once it was out, I felt 10 times better and was able to move around a lot better. The beds were not that comfortable
So many tubes and blood draws! What was this like?

- More annoying and inconvenient than hurtful and scary. I was just used to it, I guess
- Scary
- I got used to it pretty quickly. There was so much going on that I didn't notice it that much
- Generally fine, except for the arterial line, which really hurt
- I don't really remember all the tubes and stuff from when I was in CICU. That was where they removed the neck tube and breathing tube. After one full day in the step down unit...when the drainage stopped is when they removed the chest tubes...what a relief. I kept the two IV ports, one in each arm, up until the day I left. It was great getting everything removed to go home
- Because of the breathing tube, you won't able to talk when you wake up. That freaked me out. Oh, and that if I ate something after they took the tube out, I may throw up...which I did, that first meal. The medicines will sometimes make you queasy. And the chest tube is the worst part, but once that comes out you will feel a lot better
What do you think of your scar?

- It’s pretty cool
- As I have aged, I have gotten a little used to it. It’s hard being a teenage girl with a scar though
- I don't really want people to see it right now. I'm not embarrassed about it, I just don't want the attention
- I never thought it was cool. Never
- Mom said I was part of the zipper club. It has been five months since the surgery and the scar is starting to fade. It used to bother me, but now it's no big deal
Headed home! How long were you in the hospital and what was it like going home? Did you celebrate?

- I was there for three days. Going home wasn’t that bad. My dad is a good driver, so I wasn’t too worried. And I really didn’t celebrate. I just got to do what I kind of wanted.
- 10 days in the hospital
- I was in the hospital for five days after surgery. I then stayed in the Children's center for five days, then we went home. Getting home was awesome! I missed my own bed. We celebrated by having dinner together and getting back to normal.
- I was in the hospital for four days. It was great to go home! I wanted to sleep in my own bed. Mom stopped and got me Chick-fil-a on the way home. As soon as I got home, I went into the office and got on my xbox and gaming computer to play for a little bit.
What was recovery like at home?

- Slow

- I had more energy

- By the time I got home, I was feeling really good. So, I was just bored since I couldn't go back to school yet. My dad and I would go for walks every day to get my energy back. I started working on homework the day after we got back (which was one week after I was discharged from the hospital)

- Mom made me take it slow for the first week. My room is upstairs but I didn't have any problem walking up the stairs. She would make sure I took my medicine on time. I only took the strong pain meds at night to help me sleep and then had Tylenol during the day. The pain wasn't too bad
Feeling normal again! How long until you felt back to normal after surgery?

• Normal is different for everyone, but I guess maybe three to four weeks
• The night I ate a real meal with my family. We went out to eat eight days after my surgery. That felt normal. Also, getting back home made me feel normal - which was 11 days after surgery
• My school was on break the week after I got home, so I went back to school about two weeks after surgery. It took about six weeks to feel more like myself
What advice do you have for other kids?

• Don’t be stressed out. The doctors all know what they are doing and don’t be scared

• I think kids bounce back quicker than adults

• Don't stress about it and don't think too much about it before; you can't do anything to change it. It's one week of discomfort. After the first week, you can get around and get back to your life

• Ask questions...my doctors were open and honest, so I felt like they knew what they were doing and that helped ease my mind. You will start feeling like normal again. I like to say I am a superhero because of what I have been through
Advice for the parents from the parents

1. Don't let this define your child by making a big deal of it. They take cues from you - if you're okay, they'll be okay
2. It's a big deal, but statistically, this is a very safe procedure - look past it, not at it
3. Bring extra blankets to the hospital - while my son was hot all the time, I was cold, very cold
4. Consider bringing an airplane neck pillow to the hospital - we found it to be helpful when sleeping in a chair
5. If you are traveling for the surgery - see if there is a Ronald McDonald house or similar in the area that you can stay in - this helped a lot - first, while we slept at the hospital (my son didn't want us to leave him at night), we went back to the house to shower and change clothes - and on occasion take a nap. Also, once we left the hospital but weren't cleared to go home yet, it helped to have a house setting to be in. We could watch movies (in a room that wasn't where we also slept), eat at a table, cook meals, and just feel normal. We would have gone nuts in a hotel room
6. Bring snacks to the hospital - we used protein bars. Hospital food choices weren't that great - and often times I was too distracted to remember to order food, but we really needed to keep our energy up so we could focus on our son - the protein bars were a convenient way to get nutrition. I also took some Airborne just to boost my immune system knowing that I'd be low on sleep
Advice for the parents from the parents.

7. Sleeping, I generally tried to revert back to when I had a baby- sleep when he does. But make sure to try and get some sleep. You aren't good for your child if you get sick.

8. I brought a refillable, insulated water bottle which was really handy. This helped me to always have ice water to drink; make sure you stay hydrated.

9. Kids bounce back! Seriously, their bodies are hard-wired to heal. It's not going to be as bad or as stressful as you are afraid it will be. Eight days after surgery we were going out to eat as a family. Two weeks post-op, he was doing homework and completely off pain meds and living day-to-day life.

10. You will likely have friends and family asking what they can do to help. A few ideas - if you have people local, letting people bring you meals at the hospital is huge. Helping you to feel good helps your child. If they are willing to do it, let them - don't be afraid to ask. We had relatives bring us lunches or dinners - it was so nice to get hot food. Once out of the hospital, we had a bunch of people decide to bring us meals - my natural pride was to say no - feeling silly because I am perfectly able to cook. But, having the food brought in has allowed us to just enjoy each other and being home.
11. Kids don't need to know all the details about each surgery and it's all sometimes simply too overwhelming. So let them guide you and be truthful. When my child got to her teens, she really appreciated talking to a trusted doctor or PA, too.

12. Always stay with your child—no matter how wonderful the nurses, there's nothing like a mom or dad nearby, especially when doctors are coming around and assessing what to do. At the same time, give your kid some space. Let them read, be on their phone, whatever gives them some control and some comfort.

13. Perhaps the greatest advice—know that you know your child better than anyone else. Don't ever, ever hesitate to ask questions and seek answers when you sense something isn't going right.
• “I always feel honesty is best with everything but I guess you have to judge how much you tell your child based on their age and maturity level. My child knew everything I did and researched A LOT. I compiled a notebook that I kept doctor appointments in, info about his team of doctors, info about the procedure, info about the hospital and anything else I could think of. I had it with me at the hospital and went over it with my son before we went to the hospital. I wanted him to know, as a mom...I did my part to make sure he had the best team to operate on him.”
Advice for the parents from the parents (continued)

• “My child was 11 years old when she had her aortic surgery, and at that point, she had already had several surgeries. This was an age when preparing for and recovering from surgery became more difficult, as we had to deal with the emotional aspect with her, not just with the physical part. Children with chronic medical issues need to have control, as there is such a large aspect of their life that is out of their control. As a parent you must give them control when you can. Let your child talk to the doctor directly. Do not answer questions for them that they can answer themselves. I knew that at some point, my child would need to be able to advocate for herself, and if I held on too tightly to all the information and spoke for her, she would not have access to all the resources she needed to communicate and advocate for herself. Allow your child to grieve and be scared of this process, but do not allow them to be sick children. Their illness will never be forgotten, but it doesn’t need to dominate their lives. We as parents must give LDS kids the power to live their lives despite the obstacles they face.”