



Life After Heart Surgery

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Tips from Adolescents and Young Adults

Will life get back to normal?

Life after heart surgery is different for everyone. A lot will depend on potential complications that can arise after surgery, both short-term and long-term, and the nature of the heart surgery itself. However, it's important to realize that most everyone feels like they can eventually get back to a “normal” life (or at least as normal as it was before the surgery).

“At times, life after surgery was frustrating. It can be difficult to have a complicated medical history because it takes more time and consideration in certain situations. I have found that the more I learn about my surgery and specific medical experience, the more comfortable I am in dealing with issues such as medical forms, traveling to developing countries, and finding activities that work for my body.”

-Lisa, age 21

How do I advocate for myself?

It is important to advocate for yourself by talking with your healthcare team or talking to your family about your health. If you feel something is not right, speak up. You know more about your body than anyone else.

“A few years ago, my cardiologist began asking me all of the questions at my yearly appointments instead of my parents. She told me as I look toward the future and living on my own, I have to be able to advocate for myself when it comes to medicines, appointments, and any health changes or problems

I may be experiencing. When I was young, I was sometimes afraid to tell my parents or my doctors if something was wrong or out of the ordinary because I didn't want to go in for surgery again. One example was after my first pacemaker generator replacement in 4th grade, it would occasionally do a weird beating thing inside my chest. I let this haunt me for a year until I finally told my mom what was going on. At my next appointment, I told my pacemaker doctor and it turns out it was just my sensitivity to the new pacemaker changing rates. If I had spoken up right off the bat, it would've saved me a year of pointless worry and anxiety. That is a lesson I take with me to this day, reminding me that if something isn't right, I must speak up and let someone know. It could save me from further worry or other complications in the long run, especially if it turned out to be something serious."

-Brady, age 18

What about getting back to sports and other activities?

Getting back to sports and other activities is an important topic to discuss with your heart center healthcare team because participating in activities you enjoy can have a lot to do with your quality of life. The nature of the sports, exercise, or activities that you can safely pursue will depend greatly on the type of heart disease that you have. Most teens and young adults are able to find activities that are safe and fun, even if they are different than their pre-surgery activities.

"Around 8 months after surgery I returned to competitive rowing. I wanted to get back to regular exercise, but rowing turned out very painful for my back and chest. I realized I needed to find a different sport that was right for me, that I was able to do pain-free."

-Kelsey, age 17

"For me, the moments where I had to cope the most were not only right before surgery, but also a while after surgery. Questions like, 'Why do I have to go through this?' or 'Why do I have to quit soccer?' often came up in my head. I spent a long time after my surgery being bummed that I got out of shape for soccer and that all of my friends carried on without me.

It wasn't until after my surgery that I discovered programs such as NCL (National Charity League) and VOICE (Volunteer Outreach In Communities Everywhere). I absolutely love volunteering and am able to fully participate in it, even with my heart defect. I also love to sing and play the trumpet in my school band. As soon as I realized I can still participate in activities that I love, even if they were new to me at the time, I was able to cope with my deficiency."

-Raegan, age 17

"I continue to go to my cardiologist to make sure I am still doing fine. I have learned that sometimes the fixes for heart defects might not work as you grow, so recommendations may change with time.

Because heart problems like mine can cause you to tire more easily, I had to find sports that didn't involve a lot of running. (Examples: baseball/softball, golf, bowling, etc.) I was also able to find activities I enjoy and don't have to

strain myself to do. (Examples: kneeboarding, wakeboarding, water or snow skiing, snowboarding, etc.)”

-Brady, age 18

How can I talk to my friends about my heart?

If you are like most teens and young adults, your friends are very important to you. You may have a hard time telling them about your heart defect or even wonder if you should tell them. Once you do tell your friends, they may not know what to do or say. Sometimes, friends feel sad or awkward. Sometimes, they might not stick around. But for a lot of teens and young adults, your friends will be an important part of your support as you heal after surgery.

Everyone has different ways of talking to their friends—try whatever works best for you. If you need ideas or help, these insights from others might help:

“My friends call me “Cyborg” – in a friendly way!”

-Katie, age 18

“Sometimes when people see my scar they get a little awkward or start asking a bunch of questions about it. This has gotten pretty annoying over the years, mostly because of the constant reaction, ‘OH MY GOSH, ARE YOU OK?’ or, ‘THAT’S TERRIBLE!’ That reaction makes me feel awkward because to me, it’s normal and not a big deal. I have learned to be prepared for someone to freak out when they hear what I have to tell them. I have also learned that most of the people that ask me what the heck happened aren’t science majors. If you don’t feel like going into detail, you don’t need to. Usually the key thing they want to hear is, ‘Yes, I’m OK.’ What I tell most people is, ‘I have had two open-heart surgeries; one when I was a baby and one in middle school. I was born with a heart deficiency and after my heart grew, I needed another surgery.’ Short and sweet is how I keep it, unless I feel like telling them what I went through and how it really is a big part of my life.”

-Raegan, age 17

“If I know the person has taken Health in school and knows the anatomy of the heart, I go in depth. They love to hear about it and I feel really smart telling them. In terms of my pacemaker, some of my friends call me the bionic man. I think it’s pretty funny.”

-Brady, age 18

What about travel?

For many people, traveling is a part of young adult life and development to adulthood. If you are going on a trip, it is important to talk to your cardiologist. Things to consider include:

- Medicine: Get extra medicine for your trip just in case.
- Packing: Bring your medicine in your carry-on so it won’t get lost.
- Security: Going through security may take a little longer if you have any metal in your body, like a pacemaker.

To Learn More

- Heart Center
206-987-2015
- Your healthcare provider
- seattlechildrens.org

Free Interpreter Services

- In the hospital, ask your nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

- ❑ Hospitals: Plan ahead and find the hospitals where you will be traveling, so you can get help quickly if you need it.

“My family had a vacation planned to Switzerland and Italy before we had scheduled my surgery. I was still dealing with complications near the time we were planned to leave. My mom was very wise in contacting hospitals in the area we were staying, because about 5 days into the trip I had another episode of pericarditis and had to go to the hospital and go on steroids.

I also travelled to Laos more recently. I had to be very careful as I was going to a very rural area of Laos with little to no medical aid available. I talked with my heart doctor a lot before I left, and I brought steroids with me in the case that anything happened.”

-Kelsey, age 17

“I applied to study abroad in Peru and Ecuador for my junior year of college. On top of the application forms, letters of recommendation, and scholarship essays, I also had to complete several medical forms because of my heart condition. It was definitely frustrating at times because I had to do a lot of coordinating with my doctors and the study abroad office in order to show that I was ‘fit’ to travel. But despite this, the program has officially approved me and I just bought my plane tickets! My heart condition can make travel more complicated, but I don’t let it stop me from applying for such a valuable experience.”

-Lisa, age 21

“Because I have a pacemaker, I usually can’t go through the metal detector. Instead, when I go up, I tell the security person I have a pacemaker and they have someone give me a pat-down. This was a little awkward the first time, but they explained what they were doing. I travel often enough, so it has become a usual thing. If the airport has a full-body scanner, I take advantage of it. It saves a lot of time and trouble, and I like avoiding the pat-down.

I always pack my medicine in my carry-on. That way, if your checked baggage gets lost in transit, you will still have your medicine. I pack enough for the whole trip, and then a few days extra just in case it is needed.

There is usually a hospital nearby wherever I travel, but if I am going somewhere that doesn’t, I make sure to do some research on where the hospitals are located to see if I will be near one just in case something did happen. I make sure I know how to contact emergency services if I am in a different country.

-Brady, age 18