**Preparing for Your Heart Surgery**

**Tips from Adolescents and Young Adults**

**Planning for the day of surgery**

There will be a lot of discussion with your heart center healthcare team before your heart surgery. Most of it will focus on the surgery itself and less on the details of life in the hospital. This information is meant to help you feel more prepared for entering the hospital and for your recovery after surgery.

**What are the key things I need to know?**

- You might not see your primary heart doctor (cardiologist) the day of your surgery. Depending on how long you stay in the hospital, you may not see them afterward, either. However, you can trust that your primary heart doctor is working with your surgeon or interventional cardiologist very closely.

- You will meet a lot of different people in the hospital besides doctors and nurses. This may include social workers, echo techs (echocardiogram technicians), physical therapists, nutritionists and respiratory therapists. It can get really confusing. Feel free to ask anyone who they are and what they are doing. They have your health and safety as their highest priority and are part of your care team.

- You might have to share a room. Sharing a room can be a little frustrating at times (especially if it is with a baby). Families and medical staff will work hard to make sure you are comfortable. If you are not, let someone know.

- You may have to change rooms more than a couple of times, especially if you are in the hospital for a long time. This is usually because some rooms have special equipment that is necessary for certain patients.

- There will be a place for a family member to sleep in every room you have. Most people have one parent stay with them in the room at night, although that is not required. Most people find it helpful to have a family member in the room with them to help keep track of everything that is going on. It can be a confusing time with unfamiliar people, a new setting and the influence of pain medicine. Having someone familiar there can be reassuring.

- You will be given information about what to do the day before your surgery, with a checklist of items. Most of them are fairly self-explanatory. But some of them may be surprising, like making sure you have removed all nail polish. This is because the doctors and nurses sometimes need to look at the color of your fingernails as a sign of appropriate blood flow. If you have any questions, you can call the number listed on the checklist.

**What should I bring to the hospital?**

Bringing items from home can help you feel more comfortable when you are recovering. You will get a hospital gown when you go in for surgery, but you may want to wear your regular clothes as you are recovering.
Clothing and comfort items

- Soft clothing that won’t irritate your wound, like basketball shorts or sweats and t-shirt
- A comfortable bra that won’t hurt your chest area (for girls). Avoid bras with an underwire as they may irritate the surgical site.
- Clothing that you can layer if it gets too cold or too warm
- A few extra pairs of underwear and lots of socks or fuzzy slippers
- Special comfort items, like a favorite blanket or pillow
- Ear plugs

“I found it most comfortable to wear basketball shorts and a loose t-shirt. I got a hospital gown when I went in for surgery, but I put my regular clothes back on when I left recovery. I wanted something soft that wouldn’t irritate my wound. I was really glad I remembered to bring a change of underwear to put on before I headed home because I was still wearing the ones I wore during the procedure and in my recovery bed.”

- Brady, age 18

“I brought a small bag full of warm and comfortable clothes. For girls it is important to bring a comfortable bra that won’t hurt your chest area. Prepare for all temperatures, so bring layers. One item I wish I had brought more of is socks! Bring lots of socks!”

- Kelsey, age 17

“When I got my surgery in 7th grade, I brought my blankie to the hospital because it reminds me of home and offers me comfort. I would definitely bring anything that comforts you and that includes clothes, stuffed animals, even a comfy bra if you choose to wear one.”

- Raegan, age 17

Entertainment and electronics

Listening to music, watching movies, reading books and other entertainment can help to pass the time when you are recovering. You will have low energy. We have a free high-speed internet connection for patients and families to use while at Seattle Children’s called SCH-Guest.

All of the rooms have a TV and an iPad that offers entertainment and movie streaming apps, as well as access to the GetWell Network. On the GetWell Network you can listen to music, watch movies, play games, and surf the internet.

You may want to bring your favorite things from home too. If you want to use specific apps or programs, it can be helpful to have your own device. Some TVs in the hospital are not suitable for personal gaming systems, so
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hand-held devices are best. Here are some items that others have brought from home:

- Smart phone, tablet or laptop with your favorite apps and music playlists
- Favorite books and card games
- Hand-held gaming systems

“I quickly found out that Seattle Children’s has free Wi-Fi! Bringing a computer was a great way to stay entertained with internet access and movies, especially because I was in the hospital for few days. It also helped me keep in touch with friends.”

-Kelsey, age 17

“I brought my iPod because I love my music and it didn’t only give me something to do, it also helped me get back to sleep after procedures in the middle of the night. I also wished that I had brought some movies to the hospital because there was a TV and a movie player in the room.”

-Raegan, age 17

What about school?

If you are preparing for heart surgery during the school year, you will want to talk to your teachers and make a plan. If your recovery time will be short, it can be helpful to get assignments done early. Ask your teachers what they expect from you. Keep in mind that you may be too tired to do school work when you are recovering.

“My teachers were really understanding when I told them I was going to be gone for surgery. They gave me plenty of time to catch up on my work. My teachers gave me most of my work ahead of time, and I made sure to finish it all before going in for surgery.

I found it helpful to schedule the surgery for a Thursday or Friday because then I was able to get my homework done for that week before I went in. I had the weekend to recover and finished everything else on Sunday and Monday. By the time I went back, I felt much better, had more energy, and was almost completely caught up.”

-Brady, age 18

“As a college student, I was worried about missing school for my surgery, since things like attendance and grades are not taken lightly. However, my professors were very understanding and let me take my final exams early. It definitely helped to approach them early on.

-Lisa, age 21
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“I knew I was going to miss a lot of school when I was going in for surgery and I really did not want to be doing homework while I was healing. I had several meetings with my teachers and my principal beforehand to let them know what the next few weeks were going to look like. My teachers were so generous and “froze” my grades. This meant I could just pick up where I left off when I returned to school. This made it really easy on me and a lot of stress was taken off my shoulders. A reason that they were so generous was because I made time to sit down and meet with them. I found that communication was key in situations like these.”

-Raegan, age 17

How do I cope with being nervous about my upcoming surgery?

“Surgery was a scary thing. It helped to remind myself that I would come out the other side, that I was in good hands, and that it was for the best. Talking with my friends and family helped take my mind off it and let me know that I have others who love and care for me that would be there through it all. For me, prayer really helped me feel better and made me stronger.”

-Brady, age 18

“I had not had surgery since I was an infant (which I obviously did not remember) and so I was quite nervous about having a surgery in my early 20s. What was most helpful to me was to reach out to others who have gone through similar experiences. It helped me feel calm and prepared.”

-Lisa, age 21

“I found that surgery can take a lot out of you mentally. Even before surgery, as mine was planned, I was a little nervous. I wouldn’t say scared, but still anxious of what was going to happen to me. What made me more nervous was that my parents were nervous. Right before going into the operating room was the scariest moment for me. Right after surgery was a blur for a week or so. As recovery was a longer process for me with complications, I was tired and felt like I would never get better, but I stayed hopeful for better days, and they came.”

-Kelsey, age 17

How do I involve family and friends?

Family and friends can be a huge help, but keeping everyone informed can be tiring. It can be helpful to use social media or email to keep in touch. Sometimes it is helpful to have your parents give updates. Don’t be afraid to tell people not to come visit if you are too tired. If you are up for it, short visits with friends and family can be a welcome distraction.
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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.

“I found that keeping friends and family updated on your health can be very stressful. During my hospital stay I kept in touch with friends through Facebook. My parents were ultimately the ones who kept my relatives updated as I was very out of it when I got out of surgery. A few weeks after surgery I was able to speak with them, but you shouldn’t feel like you have to talk to anyone until you truly feel up to it! A great way to keep lots of people updated at one time is a private blog or website.”

-Kelsey, age 17

“Everyone wanted to know how I was doing and what exactly was going on. Sometimes this got annoying or complex to constantly be re-explaining what was happening to me. I had to remember it was because these people care about me! I made sure my friends knew that they could visit me if they wanted to, but I also wanted to make sure they knew I needed rest and relaxation time. Don’t ever be afraid to explain that you need some space sometimes because they will definitely understand. I found that friends might feel awkward asking about what’s going on so, if you’re comfortable with it, invite them to ask questions.”

-Raegan, age 17

How much time do I need to budget for recovery?

Recovery is a very individual process and varies with each person depending on the surgery and your overall health. If you are getting a pacemaker, you may start feeling better in 3 to 5 days. Open heart surgery can take weeks or months to recover from. Give yourself permission to take the time you need to heal. When you get back to daily activities, like exercise or sports, you will start to feel like yourself again. However, remember to talk to your heart healthcare team. When you can return to sports and regular activities will depend on the type of surgery you had and the details of your recovery.

“After my pacemaker surgery, I started feeling much better after about 3 to 5 days, but the wounds took at least a month to heal completely.”

-Brady, age 18

“Not until a year after surgery (including my complications) did I feel entirely back to normal. I think it is important to get back to regular exercise as soon as possible, because that helped me feel healthy and feel myself again.”

-Kelsey, age 17