

The logo for the Adult Congenital Heart Association, featuring the text "Adult Congenital Heart Association" in a black, sans-serif font, with a small red heart icon between the words "Heart" and "Association".

Adult
Congenital
Heart ♥
Association

Open Heart Surgery:

The Congenital Heart Patient's Perspective
and Tips on Preparing for Surgery
and Recovery

**Adult Congenital Heart Association's
Heart to Heart Peer Mentors**

To our dear readers,

If you are reading this book, you must be going through a stressful time, and for that, I am sorry. One of the things I am most grateful for is the congenital heart community and the wonderful people who are a part of it. Whether you are newly diagnosed, need an intervention for the first time in your adult life, or have had several surgeries, you are part of this amazing community, and I hope you can feel its heartfelt strength supporting you through your journey.

When I was preparing for my second open heart surgery (my first as an adult), I thought I had done everything I could to prepare myself. I listened to webinars, asked questions, and connected with my heart friends. Yet, I felt totally unprepared once I was actually going through recovery! While you may never be 100% prepared, the intent of this book is to offer the patient's perspective so that you can be better prepared about the real-life experience of open heart surgery and the recovery process.

This book is a collaboration of true stories and tips that the Heart to Heart Peer Mentors have personally experienced. Each of the contributors to this book have gone through what you are going through. I hope this collection brings you some comfort, strength, knowledge, and peace in preparing for this next part your CHD journey.

I wish you the best.

Amy F-B.

Adult Congenital Heart Association
Heart to Heart Peer Mentor

Table of Contents

Finding Out You Are Having Surgery	4
Meeting with Your Surgeon.....	9
Emotional Preparation.....	13
Surgery	16
Hospital Stay	19
Immediate Homecoming	23
Returning to “Normal” Life Before Post-Surgery Restrictions End	31
Immediately Beyond Post-Surgery Restrictions	33
Long-Term Recovery	36
Preparing Friends, Family and Children	38
Exercise: Pre- and Post-Surgery to Enhance your Recovery	41
Traveling for Surgery	50
Advanced Care Directive	52
Family and Medical Leave Act (FMLA Law)	55
GLOSSARY OF TERMS	59

Finding Out You Are Having Surgery

Section Author: Ken W.

Finding out that you need to have open heart surgery is scary. Whether the procedure will be your very first one or you're a "veteran" of the operating room, it is often very unsettling news to receive. While everyone's experience with surgery is different, this section is intended to provide some general guidance and tips on how to prepare yourself and your loved ones for your upcoming procedure.

To borrow some good advice from the Boy Scouts, one of the best things that you can do is to "Be prepared." Arm yourself with as much information as possible—to the degree that you are comfortable. Some people will want to know all the details about what the procedure and recovery will entail, while others only want to know the basics (for example, how long will I be in the hospital? How long will I be off work?).

This topic has been divided into three primary sections:

1. Preparing mentally and emotionally
2. Preparing physically and medically
3. Preparing logistically

Preparing Mentally and Emotionally

For some people, the mental and emotional aspect of having surgery can be more unnerving than the physical pain associated with the procedure. Here are some tips on how to care for yourself mentally and emotionally as you prepare for your surgery:

- Find a support network. This support network can include others who have gone through similar experiences as you and have had a similar procedure or surgery. The Adult Congenital Heart Association's (ACHA) Heart to Heart Peer Support program¹ and Online Community² are two great resources where people who have undergone open heart surgery gather to offer support and information to others. These resources are available at no cost. Additional surgeries can come as a surprise to many with congenital heart disease who may have been told they were "fixed" as a child. Many in ACHA's Heart to Heart Peer Support Program and the Online Community can also relate to feeling surprised. The support network could also include a close family member or friend so there is someone who has personal knowledge of your exact circumstances who can lend support before, during, and after surgery. An additional support network may include a therapist who specializes in providing support to those undergoing medical

¹ Heart to Heart Peer Support Program. Available at: <https://www.achaheart.org/H2H>

² ACHA Online Community. Available at <https://community.achaheart.org>

issues. A therapist can often offer suggestions on coping mechanisms for any pre- or post-surgery concerns or anxiety.

- Talk to your doctor if you are having problems with depression, anxiety, sleeping, or coping with your daily life. You may benefit from talking with a therapist and/or taking medication. Some therapists can assist with cognitive behavioral therapy and/or teaching relaxation techniques. Some techniques include breathing exercises and guided imagery.
- Distraction is a great coping mechanism when dealing with pre-surgery jitters. Whether it is beginning a new walking routine, starting a great book to get lost in, committing to a cleaning/organizing project, or watching your favorite television series on Netflix, if it brings you some relaxation or gets your mind off of the surgery, it can be beneficial.
- Get a massage or two in the week prior to surgery. This will help blood flow more freely and help keep you relaxed.
- Some people find meditation or some form of mind/body exercise (such as yoga or tai chi) to be very helpful. See our Section on [Emotional Preparation](#) for additional tips.

Preparing Physically and Medically

Any medical procedure inherently involves some level of risk, and open heart surgery (sometimes abbreviated OHS) is certainly no different. But you can help decrease that risk by getting (or keeping) yourself in the best physical shape possible. Generally speaking, the better shape you are going into your procedure, the faster you will recover. Here are a few specific tips:

- “It’s important for you to be as healthy as possible for the operation. During the two weeks before the day of surgery, it’s a good idea to keep away from people who have a cold or fever. If you develop a fever, cough, or cold during that time, talk to someone on the cardiology or surgical team to decide if the operation should be delayed.”³
- Talk to your doctor about the amount of physical activity you should be doing leading up to surgery. For some people, it’s perfectly fine to stay active (whether that’s going to the gym regularly, cycling, running, or just walking around the block). But for others, it may be necessary to wind down their activity levels in the days leading up to surgery.
- Talk to your doctor about the medicines you are currently taking and whether or not they need to be stopped (and if so, when) prior to surgery.
- “Cut back on or quit smoking, drinking alcohol, taking drugs, and drinking caffeine. Going through withdrawal after surgery will not be pleasant.”² It can also be dangerous to go through withdrawal after surgery. Be upfront with your doctor about the amount of alcohol you drink and the amount of drugs and specific drugs you take. It may be dangerous to take narcotic pain relievers for any reason with the anesthesia and pain medications that are

³ American Heart Association. Congenital Heart Defects Surgery. Available at: www.heart.org/HEARTORG/Conditions/CongenitalHeartDefects/CareTreatmentforCongenitalHeartDefects/Congenital-Heart-Defects-Surgery_UCM_307729_Article.jsp. Updated July 24, 2015.

typically used during surgery and recovery. It is very important to be completely honest with your doctor.

- “With your doctor’s approval, increase your protein and iron intake a few weeks before surgery. Do NOT gain weight unless they tell you to do so.”²
- Ask your doctor if you need to get a clearance letter from your dentist. If needed, your appointment with the dentist should be within six months before your surgery. This is important to make sure you have no dental infections (or to have them taken care of prior to surgery), which could potentially compromise your heart health. “You will be seen for preoperative counseling and testing the week before the scheduled surgery. At that visit it may be possible to arrange a tour of the hospital. Common pre-surgery tests include an electrocardiogram, echocardiogram, chest X-ray, and blood testing.”³
- “Ask your medical team to teach you some exercises to help strengthen the muscles you will need post-op. Learn how to move properly to protect your sternum. Sternal wires don’t keep your sternum stable. You will have to do that when you sit up and stand up after surgery.”² You can also see our section on [Exercise: Pre- and Post-Surgery to Enhance your Recovery](#) for more information.

Preparing Logistically

You will have a number of restrictions and limitations in the days and weeks immediately following your surgery (See our Section on [Immediate Homecoming](#) and [Returning to “Normal” Life Before Post-Surgery Restrictions End](#) for more information). Here are some tips on how to plan ahead for a smooth recovery:

- “Prepare an advanced directive and select a durable power of attorney for healthcare to make medical decisions for you if you cannot.”² See our Section on [Advance Care Directive](#) for more information.
- Compile a list of family and/or friends in advance who are willing to help. Some routine tasks to assign to others include:
 - Someone to stay overnight the first night home so you do not have to be alone in case you need help.
 - Shopping for groceries, prescriptions, toiletries, etc.
 - Assistance in driving to any follow-up doctor’s appointments.
 - Cooking and meal preparation options:
 - Sign up for a home delivery service of groceries or prepared meals.
 - Prepare and freeze multiple meals in advance.
 - If applicable, create a plan for child care and carpool needs.
 - Purchase, rent, or borrow a comfortable recliner for when you return home from the hospital. It will likely be too difficult and painful to lie flat in your bed, and a recliner is a great option for sleeping in the first days back home. If you are

purchasing one, do so several weeks before surgery to allow for any customization and delivery.

- Have extra pillows handy for when you can sleep in your bed again.
- Join Netflix or Hulu or line up your favorite (light) television shows and movies to watch.
- Have books and magazines on hand but make sure they are light reads.
- If you are into social media, consider keeping a blog, Facebook, and/or Twitter page. These are a great alternative to replying to phone calls/emails when you're exhausted. Facebook and Twitter are great for mini status updates, and the blog for longer updates.
- Pack for the hospital visit (See our Section on [Hospital Stay](#) for more information).
 - What you may want to take to the hospital: identification, insurance card, medication list and medical records, underwear, a couple of comfortable sweatpants and shirts that will be easy to put on so you don't have to wear the hospital gown the entire hospital stay, warm socks and/or slippers, books or magazines, notebook for keeping notes, travel size toiletries (toothpaste, lotion, deodorant), earplugs to help sleep when it may be noisy, a pillow and/or comforting blanket, family photo, ACHA Personal Health Passport, reasonable expectations, courage, patience, and a sense of humor.
 - What not to take to the hospital: wallet, cash, credit/debit cards, jewelry, or other valuables

Miscellaneous: What They Don't Tell You

- Tell your loved ones to always speak to you as though you can hear them, even if they're pretty sure you're under sedation and cannot. Ask them to frequently repeat important things to you even if you're not responding yet (for example, "You're in the ICU; your surgery went well; the doctors say you should be waking up in the next few hours, hour, few minutes, whatever; we love you; you have a really nice nurse; your siblings/children/whoever are doing well and send their love.")² See our section on [Preparing Friends, Family, and Children](#) for more information.
- Write down (or get a list of) all medications the doctors and nurses give you while you are in the hospital and any reactions you have to them. Also, take notes on the things your doctors want you to do to help with your recovery — both while in the hospital and when you return home. You will be hearing and gathering a lot of information while you're in the hospital, and you'll want to remember the details for later. (Yes, the most critical information will be kept in your medical records by the hospital staff, but you'll likely want to have your own notes.)² It can be hard to remember these details while on some of the medications.
- It can be awkward or uncomfortable for females if their period starts the day before surgery (or close to it), but the nurses know how to handle that. It is not unusual to start your period right after surgery (or a heart cath). The nurses can provide pads and other necessary items

when you are on the operating table or even in a hospital bed. (Nurses are well trained and have plenty of experience. Patients should not be embarrassed by normal body functions.)²

- Patience and a sense of humor are two of the most important things to include in any hospital trip.



From the Heart of Ken:

When I was in the hospital for my pulmonary valve replacement surgery, I was extremely fortunate to have some phenomenal nurses. Since I was there for over a week, there were a few nurses who took care of me on multiple days. As the nurses would make their morning rounds and greet me at the start of their shifts, I would joke with them and apologize for them having drawn the short straw that morning (when getting their patient assignments) and that they had to take care of me again. They would laugh and assure me that they were happy to do so. (I think, by comparison to others on the floor, I was actually an easy and cooperative patient.) It was just a silly joke, but I'm sure it helped to break their normal routine, and it certainly helped them remember me.

Recommended Books

[Prepare for Surgery, Heal Faster](#)

By Peggy Huddleston

From Amazon.com: “*Prepare for Surgery, Heal Faster* shows how to use mind-body techniques to reduce anxiety, use 23–50% less pain medication, and heal faster. Documented by research, it is recommended by hospitals in the U.S.”

[Back to Life after a Heart Crisis](#)

By Marc Wallack, MD and Jamie Colby

Although not specific to congenital heart disease, I read this book as I was preparing for my pulmonary valve replacement surgery and found the authors’ advice and experiences to be helpful in preparing for what to expect from my upcoming journey.

Meeting with Your Surgeon

Section Author: Deborah F-K.

Most congenital heart patients are able to schedule their surgery ahead of time. This can have both advantages and disadvantages. Thinking about an upcoming surgery can cause stress. However, having months to plan enables you to meet with your surgeon to answer your questions and prepare you physically, mentally and emotionally for surgery.

Since many congenital heart patients travel out of state to receive care and undergo surgery at an adult congenital heart center, it is important to plan and make the most of the pre-surgery meeting with your surgeon. You may also meet with a surgical nurse practitioner or physician assistant and an anesthesiologist (doctors who control your anesthesia).

Here are some guidelines for a successful meeting:

- Have your medical records and any test results and operative notes from previous surgeries (including childhood surgeries) sent to the surgeon ahead of time.
- Ask if any blood work will be needed prior to surgery, and if so, if you need to fast prior to the blood draw or if there are any other preparations that will need to be taken.
- Bring a list of current medications.
- Bring someone with you to the meeting to take notes and provide a second set of ears. You will undoubtedly be somewhat stressed, so having another person there to take notes and even ask questions is helpful. Discuss with the person ahead of time what your main concerns will be and ask that the person pay special attention to the answers to those questions. Also discuss with the person how involved you want him or her to be. For example, you may wish for the person to speak directly to the doctor if they have a question, or you may wish for them to listen only. Some surgeons will even let you record the appointment on your phone.
- Dress comfortably and in layers. Hospital temperatures vary and are sometimes very cold or very warm. You will likely undergo a physical exam.
- Bring water and a snack—the day may be long and there might not be a chance to purchase a meal.
- See if your congenital heart center has a wellness center. You may also be able to schedule a meeting with someone to learn about complementary therapies, such as massage, hypnosis, etc. to prepare for surgery and recuperation.
- If you have concerns about handling the stress of the surgery, check to see if the hospital has a social worker who can provide guidance and assistance before and after the surgery.

- If you have concerns about what your insurance will cover, you may want to make an appointment with the billing office to discuss what portion of the bill you will be responsible for and if you can use a payment plan.
- Develop a list of questions for your surgeon. If possible, send these to your surgeon or a member of his/her team beforehand. This will allow time for your surgeon to review your questions and clarify what you are asking if necessary.

Some questions you may want to ask your surgeon and his/her team are listed below:

Surgeon's experience:

- How many surgeries for *my condition* on adults with CHD are done annually at your hospital and by whom?
- What has been your success rate? Do you know about long-term outcomes?
- How many total heart surgery procedures are done at your hospital each year?
- How does the adjusted mortality rate for your hospital for this procedure compare with others in the nation? At your hospital?

Pre-surgery concerns:

- What is the best way to prepare myself physically and emotionally for surgery?
- What are the risks and complications associated with this surgery?
- What are my specific risks? How risky is my surgery overall?
- How soon before surgery should I leave work?
- What pre-surgery testing will be done and when?
- What changes in my medications will I need to make before surgery?
- How soon before the surgery will I need to arrive at the hospital?
- What items from home can I or should I bring?

Surgery and immediate concerns for after surgery:

- What has occurred that makes this surgery advisable at this time?
- What will likely happen if the surgery is not done?
- Will this operation improve health, quality of life, functional ability, or length of life?
- Are there any common complications after the operation?
- What is done during this surgery?
- Will I be able to listen to a CD or my personal music during the operation?
- What kind of anesthesia will I be given during the surgery?
- How long does the surgery usually take?
- What's the average length of hospital stay?
- How can I ensure that *my surgeon* will be doing the operation rather than senior residents? How many surgeons will be in the room?

- What is the progression of events after the operation?
- What do you do for blood transfusions? Can family members donate? Can I donate my own blood in advance?
- If I decide not to have blood products administered, does the hospital follow the official guidelines around Bloodless Care Protocols—the practice of using only the patient’s own blood during surgery.
- What type of materials are you going to use (Gore-Tex, human, porcine [for valves], mechanical [for valves] or other)?
- What will you give for pain medication? How liberally? Will I be able to give myself pain medication?
- When I wake up after surgery, will I be on a breathing machine?
- When on a breathing machine, how will I be able to communicate with others?
- How long can I expect to be on a breathing machine?
- Do you offer holistic measures such as therapeutic massage, aromatherapy, reflexology, biofeedback, or music therapy?

While the following concerns are typically not discussed at the pre-surgery meeting, you may want to ask if they will be addressed by the appropriate staff member before discharge.

- Any special travel considerations upon discharge? (for example, can I fly home, should we stop for walk breaks if it’s a long drive, should we wait a few days before driving home?)
- Will I be given a supply of medications for the trip home (if traveling a distance) and prescriptions that I can have filled at my home pharmacy?
- What type of limitations can I expect to have in daily living activities like dressing and bathing? Will I have some limitations in range of motion or strength? What type of devices to help me or clothing should I consider?
- Will I need a shower chair and/or an electric-controlled recliner? Any other things I should do to prepare myself for my return home?
- What type of support should I look to have come into my home to assist in my recovery or activities of daily living (for example, visiting nurses, assistance with bathing and dressing.)?
- Does the hospital provide emotional support after surgery? Can this be done virtually? If not, are there avenues that I can reach out to locally, either professionals or support groups, who are familiar with the type of emotional issues that I may be experiencing?
- What type of exercise regimen should I follow upon returning home?
- What type of long-term follow-up visits and testing will I need in the years after surgery (for example, doctor visits, echocardiograms, electrocardiograms [also known as ECGs or EKGs])
- When will I be able to bathe and wash my hair?
- Are there any lifestyle restrictions after surgery and for how long? (for example, driving, dietary restrictions, weight lifting, sports) Will I be eligible for cardiac rehab?

- What kinds of post-surgery medication might I be on (for example, aspirin, blood thinner, blood pressure medications, etc.)? For how long? When should I start taking my regular medications again?
- What symptoms do I call 911 for?
- How long should I plan on being out of work? Who will help with disability forms if needed?

If you are traveling for your surgery, you can see our section on [Traveling for Surgery](#) for more information.

You may also have non-medical questions concerning billing or support services. These can be referred to the relevant department in your hospital.

- What is the fee? Will you accept my insurance as payment in full? If I need to file an authorization request with my health insurance if the hospital is out-of-network, how soon can this be done, and can it include all before surgery and after surgery visits? Will you handle this?
- Will medical-related documents (for example, advanced directives or a living will) signed in my state be valid in the state of the hospital or will I need new documents? You can see our section on [Advance Care Directive](#) for more information.
- What accommodations are available for my family's stay at or near the hospital so they can support me throughout the surgery?

Emotional Preparation

Section Author: Deborah F-K.

The period of time before and after surgery is often a very stressful time for both the patient and the caregiver. Many congenital heart patients have their surgeries scheduled in advance, giving them time to prepare as best they can emotionally. The important thing is to find the way(s) that work for you.

Making a plan to prepare yourself emotionally for surgery is one way you can be a partner with your surgical team in your healing and recovery. It may take some effort, but research shows it could be⁴ well worth your time.

One of the first things you can do to prepare is to understand yourself and your comfort level with medical information. You need to understand the surgery and its risks, but you are the best judge of how much detailed information you can emotionally handle. While some people need to know every last detail and watch videos of similar surgeries, others are more comfortable just speaking with their surgeon. Everyone needs enough information to make a knowledgeable decision, but how much information you seek out beyond that is up to you.

We caution you from doing extensive internet searches. The internet is a wonderful and powerful tool but having too much information is not necessarily a good thing. Be careful about what websites you go to for your information. Your cardiologist or surgeon can suggest some trusted and reliable sites.

The Adult Congenital Heart Association (ACHA) provides some valuable resources for you as well (www.achaheart.org). In addition to reading about their many resources, you can also request to be connected with other adults with CHD. One way is through their ACHA Heart to Heart Peer Support Program, which provides one-to-one peer support and mentoring. The other option is to participate on the Online Community for online peer support. ACHA also provides an online list of adult congenital heart centers throughout the United States. Additionally, ACHA has a Facebook page dedicated to CHD patients and issues. Many of their members' stories focus on living with CHD and activities that could be helpful leading up to surgery. Overall, by connecting with others who have "been there and done that," you can get suggestions about what to prepare and what to focus on rather than worrying excessively about the surgery itself.

Don't be afraid to seek out the help of a qualified therapist if your anxiety is high. Dealing with your anxiety before surgery can help you to be more emotionally prepared. A qualified therapist can also teach you relaxation techniques to help lessen your anxiety.

⁴Huddleston, P. Prepare for Surgery, Heal Faster. Angel River Press. 2012.

Complementary medicinal alternatives have been shown to improve post-surgery pain, healing, and recovery.⁵ Complementary medicine is defined as a group of diagnostic and therapeutic practices that are used together with conventional medicine. They help, not replace, traditional medicine. Many cardiac surgery centers now offer wellness and/or complementary medicine centers to help patients learn these techniques, such as yoga and meditation. You may also be able to use some of these practices while you are in the hospital. Check with your hospital to see if such services are offered. A description of some complementary therapies you might want to explore to help reduce stress and improve healing is below. It is not meant to be an endorsement of any technique by ACHA, but an illustration of therapies you may want to explore.

Music therapy can provide benefits both before, during, and after surgery. Before surgery, take the time to listen to healing meditations to calm you. There is also strong evidence that patients are subconsciously aware of what happens during surgery and that music can condition the way patients respond.⁶ Post-surgery music can promote healing and reduce stress. One Boston-area hospital offers live harp music for patients, families, and staff. Be sure to talk with your surgeon or cardiologist in advance to see what options are available to you during and after surgery while you are still in the hospital.

Yoga is a therapy promoting meditation along with physical activity. Most patients can perform some type of yoga, even if it is just limited to deep breathing. Practicing yogic breathing can provide post-surgical healing benefits by helping patients take the deep breaths necessary after surgery. Be sure to get clearance from your medical team before resuming any physical yoga activity, particularly any movement that involves a lot of stretching and twisting of the body — especially throughout your torso.

Many patients think of religion as not just a spiritual guide, but as a healing force as well. A study by Randolph Byrd in 1988 showed that the patients randomly assigned to a prayed-for group had less need for respirators, antibiotics and water pills.⁷

Pet therapy has been shown to be a low-tech, low-cost therapy that improved mood and was meaningful to hospitalized patients.⁸ If you feel you would benefit from such therapy, ask your hospital if this service is provided.

⁶ Oz, M. *Healing from the Heart*. New York, Penguin Books, 1998.

⁷ Celtic Harpists. Boston's Children's Hospital. Available at: <http://www.childrenshospital.org/patientresources/family-resources/celtic-harpists>.

⁸ Byrd, R. Positive therapeutic effects of intercessory prayer in a coronary care unit population. *South Med J*. 1988 Jul;81(7):826-9.

⁹ Coakley, A. and Mahoney, E. Creating a therapeutic and healing environment with a pet therapy program. *Complement Ther Clin Pract*. 2009;15(3):141-6.

Other pre- and post-surgery complementary therapies include massage, therapeutic touch, and acupuncture. Use the time before surgery to explore these various therapies to find one that works for you. The National Center for Complementary and Integrative Health (part of the United States Department of Health and Human Services) provides information and research on various therapies.¹⁰

Open heart surgery patients sometimes experience depression after surgery. If this happens to you, seek help. Have your caregiver on the lookout for signs of depression so he or she can take action if necessary.

During your recovery, you will most likely have a primary caregiver. Caring for a patient after surgery can be overwhelming. Remind your caregiver that self-care is important. Perhaps someone else can stay with you for a period so your caregiver can get a much deserved break. There may also be community resources of which your caregiver can take advantage.

Taking charge of your emotional health will benefit you before, during and after surgery. See what resources are available in the hospital and in your community. Being proactive at this time will put you in the best emotional state possible for surgery and more in control of your healing and recovery.



From the Heart of Deborah

I will admit it; I was skeptical when advised to consider complementary medicine as a way to reduce my pre-surgery anxiety and stress. After researching various techniques, I decided to take some yoga body-sensing and yoga nidra classes. I had no idea how beneficial these classes were until I had to undergo a pulmonary function test for the second time. I remember the first time taking this test I often felt light-headed. However, when I took the test after several yoga sessions I found that the deep breathing exercises I learned helped me during the test.

¹⁰ National Center for Complementary and Integrative Medicine. Department of Health and Human Services. Available at: <https://nccih.nih.gov/>.

Surgery

Section Authors: Amy F-B. and Sarah W.

To patients, surgery can mean very different things—from a battery change on a pacemaker to an open heart surgery. To medical professionals, the term “surgery” does not include procedures such as a catheterization or a generator change to a pacemaker. This section focuses on true, medical surgeries—primarily open heart surgery.

Your previous surgeries and your specific anatomy may require differences in a surgical plan or technique. Hospitals also greatly differ in their specific policies, and surgeons can also differ slightly in their preferred practices. The material included in this section is very general. Speak to your surgeon and hospital staff for specifics related to your surgery.

Some general comments:

- Many patients arrive the same day as the procedure, very early in the day.
- You will likely be taken to a pre-surgery area to sign the informed consent form if you haven’t done so already, take your vital signs, and start your IV.¹¹
- You may need to wash yourself with special soap or wipes the night before or the day of your surgery.
- You may need to shave if you are hairy in the location of your incision.¹²
- When you wake up, you will likely be in the cardiac surgical Intensive Care Unit (ICU). Often, the goals to move from the ICU to a step-down unit are:
 - You are stable and awake.
 - Your breathing tube has been removed.
 - Your pain is controlled.
 - You can get out of bed.
 - You can breathe deeply.
 - You can begin to eat solid food.
- Retaining fluid is common after heart surgery.
- In the step-down unit, you will continue to walk further, continue to eat, switch to medication you can swallow instead of take medication through your IV, and incorporate physical therapy.

Your personal cardiologist may not be the attending cardiologist in the hospital. Some of the individuals who may be part of your care team include your surgeon, nurse practitioners,

¹¹ Houser, L. Preparing for Surgery and Recovery: The Physical, The Psychological and The Practical. Ahmanson/UCLA Adult Congenital Heart Disease Center, Los Angeles, California.

¹² Patient Guide to Cardiac Surgery at the Massachusetts General Hospital. Massachusetts General Hospital.

Available at: <http://www.massgeneral.org/heartcenter/assets/pdfs/patientguidesurgery.pdf>.

physician assistants, staff nurses, nurse patient liaisons, social workers, nutritionists, speech therapists, physical therapists, occupational therapists,¹³ respiratory therapists, anesthesiologists or pain management specialists, and patient care associates.¹² Depending on the specific other diseases or conditions you may have, several other specialists may be part of your care team. They are all part of the team who care for you, but it can be confusing to see so many people. It is important to ask who is the “primary” team, or the doctor and related staff who will be making the primary decisions about your care. This can change during your time in the hospital from one doctor to another doctor, and it is important to know who is “calling the shots”—in addition to you as the patient.

Mechanics

Below is a brief description of various lines and tubes that you may be connected to when you wake up and throughout your hospital stay. The lines and tubes are important because they continuously monitor your blood pressure, heart rate, heart rhythm, blood pressure, and other body measurements.¹²

Endotracheal Tube (breathing tube):

- A breathing tube goes through your mouth and down your windpipe. The tube is also connected to a ventilator that breathes for you. You may wake up in the ICU with the breathing tube still in place, which will help you breathe until the anesthesia wears off (approximately 4-8 hours). Staying awake will help you breathe on your own more.
- You will not be able to talk while the breathing tube is still inserted. You will be able to use your head to nod “yes” or “no,” and you will be able to write on a pad of paper so that you can communicate.
- The breathing tube will not hurt, and you will be able to breathe through it.
- The breathing tube also keeps your lungs free of mucus or other secretions.
- Your breathing tube will be removed when you are fully awake. Your throat may be sore for a few days after it is removed.

Intravenous (IV): An intravenous line (IV) is a small, flexible tube that connects to your body through a vein, most often in your arm. It will serve as a method to give you medication.

Arterial Line (A line): An arterial line (A line) is an IV that is placed into an artery at the wrist, which can be used to draw blood and monitor your blood pressure.

Pulmonary Artery Catheter (PA line): A pulmonary artery catheter is placed into a vein in your neck to measure the pressures in the chambers of your heart.

Cardiac Monitor (or telemetry): A cardiac monitor measures your heart rate and rhythm similar to an EKG.

¹³ Nemours Cardiac Center. Adolescent and Adult Congenital Heart Disease Care Program. Alfred I. DuPont Hospital for Children. Wilmington, DE.

Blake Drain: A Blake drain is a small tube to drain fluid from your lungs. Buildup of fluid in the lungs for the few days after surgery is normal.

Chest Tube: A chest tube also drains fluid from your chest cavity. It is often removed the day after surgery.

Urinary Catheter (Foley Catheter): A urinary catheter is placed into your bladder to drain urine. This will typically be removed when you move to the step-down unit.

Temporary Pacemaker Wires: Temporary pacemaker wires are small, flexible wires that are connected to the surface of your heart at the time of surgery and come through the skin to attach to a temporary pacemaker, if needed. These wires will be removed within the few days of surgery.

Patient Experiences

You may be offered a mild sedative prior to surgery, and you can choose to take this or not to take it. Sometimes you are wheeled into the operating room on a gurney, and sometimes you are allowed to walk in to the room.

If you want, ask to meet as many members of your surgical team as possible before you are placed under anesthesia or sedation. You may not remember their names, but many patients feel more comfortable when they recognize the faces they see during and after the procedure.

If you will receive general anesthesia, ask your anesthesiologist how it will be administered. You may wish to count down with your medical teams. Confirm with your anesthesiologist how you will receive pain medication when you wake up.

Many hospitals provide your family with a beeper or other notification system to give them updates during your procedure. Make it clear to your family who may stay at the hospital during your surgery when you want to see them—as soon as possible after the procedure or only when you have requested them to be brought to you. You should also tell the nursing staff so they can make sure your wishes are honored.

If you are concerned about the breathing tube, be sure to discuss your concerns with your surgical team prior to your surgery. If you think waking up with the breathing tube will trigger anxiety for you, talk to your doctor and his or her staff about what they can do to help make you more comfortable. For many people, visualizing this process ahead of time, even if you are not sure how you will respond, can prepare you.

Most operating rooms are kept cold. If you are concerned about the temperature or the temperature contributes to your pain, ask to have parts of your body not involved in the surgery draped.

Hospital Stay

Section Author: Sarah W.

Coming to the hospital well prepared can make a difficult time feel less intimidating. Here are some suggestions to help you get ready for your hospital stay.

What to Pack

You want to be comfortable during your hospital stay, but remember that you have new incisions, IVs, other tubes, and monitors. You can take your own pajamas or other comfortable clothes. However, they may be ruined by stains. Your doctors, nurses, and other caregivers will need to get to parts of your body frequently, so traditional clothing may mean changing several times. Be sure to pack comfortable clothes for your trip home from the hospital.

You may also want to bring one or two small special items, such as a photograph or inspirational card, to tape on your wall during your stay. An old pillow or favorite blanket may be nice to have, but it could also get stained or lost. If you bring a pillow, put it in a colored pillow case to make it stand out from the white hospital pillows.

If you chose to stay in the hospital gown, consider packing an old robe that would not be missed if it were to be stained or ruined beyond repair. The robe can be worn, draped around your shoulders, or placed over you like a blanket as needed.

Take plenty of pairs of comfortable socks; socks with non-skid bottoms are good. If you don't have non-skid socks, you can wear regular socks under non-skid socks that the hospital may provide.

If you are a person with breasts who will have a chest incision, you will want to make sure your breasts are properly supported to avoid pulling on your incision. You will want to buy some additional post-surgical bras for use as at home. Look for ones that close in the front, do not have underwire, and are well padded both in the straps and in the band of the bra. Often, mastectomy bras can be a good place to start, but make sure that the front closures are covered before contacting your skin. Your nurse may have suggestions for good brands to try. You will want at least two or three bras so that you can wash them frequently to help avoid infections. You may feel most comfortable wearing a bra 24 hours a day for a few days to a few weeks after surgery. Some people who are very small breasted find that wearing no bra is more comfortable.

Pack activities that do not require much focus and can be put down easily when you nap. Do not count on having internet service available your hospital room, even if the hospital says that there is access. You may want to download movies or television shows before leaving for the hospital instead of relying on streaming service. Your hospital may have DVD players available. If you will be in a shared recovery room, bring headphones so you do not disturb your roommate.

Leave any valuables at home including most jewelry and any electronics you do not need. Many hospitals have a secure area where you can store valuables, but you may need to keep your items in storage until you are discharged. Ask your hospital about their specific policies.

The hospital may provide certain basic toiletries, but you may take travel sizes of your own if you want. Many patients like to have their own items for basic bathing and shaving, deodorant, lotion, lip balm, toothbrush, and floss.

Be sure to bring with you any paperwork related to insurance authorizations you may need. Also bring your Advance Care Directive if you have one. See our Section on [Advance Care Directive](#) if you need more information.

Cardiac Intensive Care Unit (CICU) or Surgical Intensive Care Unit (SICU)

Visitors are very restricted in the ICU. In many hospitals, only one visitor is allowed to stay with you at all times. Many hospitals do not allow young children to visit. In some cases, visitors are required to be 18 years of age. If younger visitors are allowed, consider if the child will be emotionally ready to see you so soon after surgery. See our section on [Preparing Friends, Family and Children](#).

Tell your loved ones to always speak to you as though you can hear them, even if they think you are under sedation and cannot. Ask them to frequently repeat important things to you even if you are not responding yet. For example, “You’re in the ICU and your surgery went well” or “The doctors say you should be waking up soon” or simply “We love you and others send their love.” You can describe to your loved ones what you might like to hear or tell them that it does not matter if they repeat themselves. Even those who are close to us may feel self-conscious about talking in this way and might need some help to prepare.

Pain medication

Pain can interfere with the healing process, but too much pain medication can also be a problem. If are uncomfortable taking narcotics, ask for a different pain medication. You have pain medication options so keep asking questions. There are no medals for tolerating pain so you do not need to be a “pain martyr.” Also, if you are in pain, you will not be able to take deep breaths needed after surgery, which are important to prevent complications such as a lung collapse and pneumonia.

Eating

Your diet may be restricted. Try to eat when you feel hungry, even if it is not meal time. If you only have certain times at which you can request food, do so even if you are not hungry and save it until you are hungry. Eating regularly, even if only in small quantities, is an important part of recovery. You also need to stay hydrated. Even if you are still on a standard IV giving you fluids, try to drink. Hydration is also important in recovery.

Menstruation

If you are a female who has a period, you may start your period while you are in the hospital even

if it is not your usual time. It may feel awkward, but this is common, and the nurses can provide you with pads or tampons if you need them. You should not be embarrassed if you need to ask for your nurse's help in changing them.

Getting out of bed

You may not want to get out of bed and move, but it will help your recovery. Start with leg exercises that you can do in bed, and work on standing and walking. A physical therapist or your nurses can teach you how to do this **safely** to avoid harming your incisions or otherwise damage yourself. You may also have IV lines or chest tubes that you need to be careful of when getting out of bed and walking. You may have restrictions on how far you can walk. Take lots of short walks as opposed to trying to do a lot of walking all at one time. If the area to which you are restricted seems dull, listen to music while you walk.

A respiratory therapist will likely to give you exercises to improve or maintain your breathing. Do these exercises to the best of your ability. They may be uncomfortable but will help you.

Excretion and Bathing

You will likely to be asked to monitor your urine output using a “hat” that is placed in the toilet and measures volume.

Anesthesia and pain medications often cause difficulty in having bowel movements or even constipation. You will likely be given stool softeners until you have had a few easy bowel movements. Showering or bathing may be restricted during the initial part of your recovery. Your nursing staff may be able to help you with a sponge bath-type of cleaning until you are able to shower. Do not be embarrassed about asking for help as feeling clean will make you more comfortable. If you shower, you may need to use a shower chair, and you may need to pay attention to water around your incisions. Do not be afraid to ask for help, particularly if you are still connected to an IV. Consider a sponge bath or shower for each day you are in the hospital to help maintain a routine that feels “normal.”

Visitors

Hospitals often have restrictions on how many visitors you can have at one time, how long they can stay, and what age they need to be. If you are having your procedure at a pediatric hospital, then you are more likely to be able to have young children visit you, if they are part of your family. If you are in an adult hospital, children visiting may not be allowed. Check with your particular hospital about their policies on visitors.

Keep your plans flexible when it comes to visitors. You may think that you will want lots of company and then find that you really do not want anyone around, or you may think you will not want to see anyone and then end up being bored and in search of people to talk to (who are not part of your medical team!). Consider talking to supportive friends and family prior to your procedure about whether they would be able to visit and the ask if that visiting can be done on an “on call” basis where you can let them know whether or not you are open to visitors. If you do not wish to be responsible for keeping people up to date, ask a friend or family member to update

everyone. This point person can also let others know if you are up to taking any calls, seeing visitors, or suggesting times for visitors so you are not bombarded with too many well-wishers at once.

Do not feel obligated to have visitors while you are recovering if you find you do not want them. Also, do not feel embarrassed if you change your mind about visitors from one day to the next. Remember, even if you do want to have visitors, it is not your job to entertain them and if you become fatigued while they are visiting, feel free to politely ask them to leave.

If you are in a position where avoiding certain visitors is necessary because they do not have your best interests at heart, discuss the situation with your nursing staff. Nurses can help to prevent certain visitors from reaching you.

Discharge

You should be given clear, detailed directions about how to care for yourself once you leave the hospital. Depending on your condition, you may need to stay at a rehabilitation center to get stronger before going home. Your discharge instructions may include prescriptions for medications or directions on any over-the-counter medications you should take; scheduling of the first of your follow-up appointments as needed with your cardiologist, your surgeon or both; and directions on any self-care for monitoring your progress. Your nurses will also review care of your incision(s) or any other post-surgical wounds. Be sure to ask as many questions as you need to in order to understand all the details. If a family member or friend will be helping you at home, include this person in the review of your discharge instructions.

Have a plan for how you will leave the hospital. Be sure someone else can drive you unless you have been cleared to drive yourself.

Immediate Homecoming

Section Author: Diane N.

Once you are discharged from the hospital, you will continue with your recovery at home. You will have quite a few restrictions to deal with after surgery. Your recovery at home may go a little smoother if you have prepared yourself and your home for your homecoming before you leave for your surgery.

Here are a few things you may want to do in advance of your surgery to prepare for your homecoming:

“Once I knew I was going to have surgery, I made a list of the things that I needed to get done. Not only did I get those things accomplished, but it also gave me something constructive to do and to focus on rather than dwelling on my impending surgery.”

- Clean your house (or have it cleaned) so you can come home to a clean environment.
 - Pay your bills beforehand if you will be in the hospital or home within a few days of when they will be due so you will not worry about them.
 - Do any chores around the house that you have been putting off or that will need to be done shortly after your surgery (yard work, cleaning out a closet, etc.) so you are not thinking about them and worry about them while you are recovering.
 - If you normally buy bottled water and other drinks in large size containers, stock your refrigerator with some in the individual size bottles so they are easier for you to handle after surgery.
 - Prepare some of your favorite foods in advance and freeze meals in individual portions so you have some meals ready to arm up when you need them.
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- Consider renting or borrowing a recliner if you don't have one so you can sleep in it if you need to (many patients cannot lie down in bed for a short time after surgery).
 - Consider finding a chair or a stool that will fit in your shower so you can sit down in the shower if you need to. Medical supply stores and drug stores sell shower chairs that are specially designed for this purpose but a sturdy lawn chair will also work and can be a cheaper option as long as it will fit your space.
 - If you have a bathtub/shower combination, put a mat in the tub so you don't risk slipping and falling.

Clothing

Make sure you have packed some comfortable clothes to wear home from the hospital. You may be puffy and swollen from the surgery and your incision will be tender. You will want to wear something that is soft, fits loosely, and is comfortable. Pick some sweats or some of your most comfortable “lay around the house” clothes. It will be a little bit hard to pull a shirt over your head

so you may want to consider a button-down shirt. If you want to use a pullover shirt or a t-shirt, it should have a large opening so you are not tugging it over your head and struggling to get it on. For shoes, pick some slip-ons or even your slippers so you will not need to bend over to put your shoes on and buckle or tie them.

For women, it is important that you wear a bra in order to keep the breasts from pulling on your

“I usually take my shower in the mornings but I found that it made me really tired, which meant I was starting my day out tired. So during my recovery, I started showering in the evening until I got a little stronger. I also brought a resin lawn chair in off of my patio and put it in my shower stall.”

breastbone. You may be most comfortable in a soft, wireless bra that is a band size larger than you normally wear due to post-surgical swelling. Sports bras, front clasping bras, and camisoles with a shelf bra will all work and are good options as long as they are comfortable for you. Your hospital may provide you with a surgical bra. Placing gauze over the incision can prevent your bra from rubbing it.

Transportation

You will need someone to drive you home from the hospital. Bring a pillow from home so you will have it to put between you and the seatbelt. The pillow will help prevent the seatbelt from rubbing on your incision and irritating it. It will also help protect your breastbone in case the driver has to make a sudden stop. If you will have a distance to travel to get home, make sure you take some pain medicine shortly before you leave the hospital. If you will be traveling home by car, make frequent stops (about every hour) so you can get out of the car and walk around to help prevent the blood from pooling in your legs. You may want to leave your pillow in the car after you get home so it will be there to protect your breastbone each time you go somewhere for the first few weeks. If you will be flying home, be sure to ask the airline for wheelchair assistance. Most airlines have a box that you can check for a wheelchair if you are making your reservations online. Otherwise, you can ask for one upon arrival at the airport. A wheelchair transport assistant will wheel you through the airport, assist you through security, take you to your gate, and then down the jet way to board the plane when it is time. You may want to ask him or her to stop along the way so you can go to the bathroom and get a bottle of water for your flight. A wheelchair transport assistant will also be waiting for you at your destination airport to assist you off of the plane and through the airport. Stand up and walk around in the gate a little bit while you are waiting on your flight. If you have a long flight, be sure to get up and walk around a little bit while the pilot has the “Fasten Seat Belts” sign turned off. See our Section on [Traveling for Surgery](#) for more information.

Assistance From Others

You should plan to either stay with someone or have someone stay with you for at least the first week or two after you are discharged from the hospital. Even though you may usually be strong and independent, this is a time to ask for and accept help from others. You will still be weak from the surgery, tire easily and be on pain medications. You may also be surprised at how difficult simple tasks like reaching up to brush your hair may have become. You may also need assistance with meals and other activities of daily living.

Showering & Self-Care

Showering can be very tiring at first. You will not be able to use the bathtub or a hot tub for a few days to a few weeks. You may want to consider a sponge bath or a no-rinse body shampoo on days that you are feeling especially tired. Consider using some travel size bottles of shampoo and conditioner to avoid struggling with the large bottles in the shower.

You may also want to consider adjusting the time of day that you take your shower to better suit your recovery schedule. You can also put a chair in the shower and sit down for your shower until you get some of your strength back. Someone should be close by the first few times you take a shower until you are stronger.

Keep your showers brief and make sure your shower water is not too hot. Water that is too hot could cause you to become dizzy and possibly faint. Try to prevent the hard shower stream from hitting your incision directly. If you had areas of body that were shaved for your procedure, you may want to try putting a little cream rinse on the shaved areas while you are in the shower to prevent the areas from itching as the hair begins to grow back.

If you have children or pets at home, you may also need some assistance with caring for them. You will be unable to pick up small children or bend over to put food in your pet's dish.

If you will be sleeping in a room alone at night, you may want to set up some kind of a "call system" using your cell phones in case you need assistance at night.

If your home has stairs, go up the stairs slowly. You may need to stop and rest on the way up if you become tired. Limit the number of trips you make upstairs at first so you don't expend all of your energy on the stairs.

You will probably not be able to drive for four to six weeks after surgery so you should also plan to have someone available to drive for you. You will need someone who can run errands for you and take you to doctor appointments, the pharmacy, and any other places that you may need to go. Consider looking into local volunteer organizations that can provide transportation should you need it.

Your recovery goals for the next few weeks will be to eat, sleep, walk and breathe.

Diet & Nutrition

It is important that you eat a nutritious and well-balanced diet as much as possible because you need plenty of good nutrition to fuel the healing process. You will probably not feel hungry, and some foods may not taste good to you for the first few weeks. This is a normal reaction to the

stress and trauma that your body has been through with the surgery. Try eating small amounts several times a day and choose foods that you know you like and will eat.

Your healthcare team may also give you some dietary restrictions that may be new to you. A common restriction is the amount of sodium, or salt, that you may have in your diet because sodium can cause your body to retain fluid. Look at the sodium content on the labels when you are shopping at the grocery store so you can make better purchases. Weight gains or losses of 2-3 pounds in one day or 5 pounds in one week may indicate fluid retention and should be reported to your doctor.

“I read the label on the canned vegetables I was using and realized that they had tons of sodium. So I switched to frozen vegetables because I noticed that they had very little sodium. I found that I actually like the frozen vegetables better!”

Keeping your body hydrated is also important. Just as you may not feel hungry, you may also not feel thirsty. Unless your doctor has given you specific fluid restrictions, be sure to stay well hydrated. Try infusing your water with fruit to perk it up a bit. Other ways to stay hydrated besides just drinking water include eating Jell-O, popsicles, and fruits that have lots of water, such as watermelon. The popsicles can work double duty as you may have a bit of a sore throat from the breathing tube, and popsicles can be soothing to your throat.

Rest & Sleeping

You will need lots of rest in the first few weeks after surgery. You may find it uncomfortable to lie flat in a bed at first. Some people are able to prop themselves up in bed with a wedge pillow or lots of regular pillows and others find it more comfortable to sleep on the couch or in a recliner.

You may experience night sweats during the first few weeks after surgery. These are normal and should go away after a few weeks, but you should report them to your doctor if you also have a fever. You may find that your days and nights are mixed up in the beginning. Even if you have been awake during the day, it is common to still have trouble sleeping through the night. Try to get yourself back into your normal sleeping routine as soon as possible. Get up about the same time each morning and get yourself dressed and ready for the day. Take at least one mid-day nap each day to give yourself some extra rest. Then go to sleep about the same time each night. Limiting your visitors for the first week or two while you are getting back to a normal routine may also be helpful.

Exercise & Activity

You may be given a walking plan to follow when you are discharged from the hospital. Walking is one of the best exercises you can do to help speed up your recovery and to get back the strength you had before surgery. If the weather is appropriate, walk outside and get some fresh air when you can.

If the weather is bad, ask someone to take you to a mall or a store where you can walk around for a little while or walk some circles inside your house. Ask someone to walk with you in the beginning so you will not be alone if you have any problems. When you are walking alone, take your cell phone with you and stay close to home at first. Remember that if you walk two blocks down the street from your home, you will also have to walk two blocks back home. Those two blocks can seem very far away when you get tired. Walk at a slow and steady pace for a few minutes several times a day to build up your strength.

Be patient with yourself and your progress. Gradually build up the distance that you walk and the length of time that you are walking. Your strength will build itself back up based how far and how long you walk, not in how fast you walk.

Spirometry

Another very important aspect of your recovery is using the spirometer that you were given in the hospital. It is important to keep your lungs clear after surgery to prevent pneumonia. Use the spirometer several times a day as instructed by your doctor. You will be surprised at how weak your lungs became in such a short time. It will be hard at first but work towards hitting your target every time.

Pain Management

You will want to make sure that you are adequately managing your pain. Don't try to be "tough" and wait until the pain is intolerable. Take your pain medications as instructed so that you are staying ahead of the pain rather than "chasing after it." You will be able to move around more, walk more, and do more things if you are comfortable and your pain is in control.

You may experience difficulty concentrating or staying interested in TV shows or books while you are taking prescription pain medication. This is normal and will go away when you are able to stop taking the prescription pain medications.

Many people are able to move off of prescription pain medications and onto a nonprescription, over-the-counter pain reliever such as Tylenol® or Advil® within the first 10 - 14 days after coming home from the hospital. Be sure to check with your doctor as to which non-prescription pain medication is appropriate for you. When you reach that point, you may still find it helpful to take some prescription pain medication at bedtime. You will want to get a good night's sleep without waking up in pain during the night due to the previous day's activities.

"I like to shop so I had my mom take me to a store for a little while almost every afternoon. It was a little outing and I got in some exercise while walking around in the store."

Besides the breastbone pain, many people also experience back and shoulder pain. It is common because the surgeon had to stretch open your ribs in order to reach your heart and because of some of the positions that your body was put in during the surgery. Many people find that back and shoulder massages are helpful in reducing back and shoulder pain. Gentle upper body stretching can also be helpful. Some people, especially side sleepers, find that sleeping with a pillow or stuffed animal against their chest helps to prevent their shoulders from rolling forward while they are sleeping, which can cause some added stiffness and achiness in the morning.

You may find yourself constipated as narcotics for pain can cause constipation. Also, iron supplements, which are sometimes needed after surgery for a short time, can also cause constipation. Make sure you follow the instructions from your doctor on using laxatives. There are also some things you can add into your diet every day to help keep things “moving” along. Unless you are on specific fluid restrictions, stay well hydrated. Make sure you include plenty of fiber in your diet. Include a few prunes in your diet and drink some prune juice or plum juice each day.

Sternal Precautions

You will be given some restrictions, sometimes called sternal precautions, to follow when you are discharged from the hospital. Remember that the breastbone is a bone that had to be broken for your surgery. Like most broken bones, it will take several weeks for it to heal completely. Unlike a broken arm or a broken leg, your breastbone will not be able to be in a cast during the healing process. The sternal precautions will help you to keep your breastbone stable and protected over the next few weeks as it heals. Sternal precautions usually include: no reaching, pushing, pulling, twisting, or bending and no lifting above 5 or 10 pounds, depending on your doctor’s guidelines. As a guide for lifting restriction, a gallon of milk weighs approximately 8 pounds.

Adapting to the sternal precautions can be hard in the beginning because you don’t realize how much of what you do includes one of these movements. It requires more “pulling” than you think to open a refrigerator door, more “reaching” than you think to get a coffee cup out of the cabinet, and more “pushing” than you think to open a pill bottle with a childproof cap. You may not be able to bend over to tie your shoes, reach up to brush your hair, or lift a gallon of milk.

Everyone’s needs in their environment are different but most people quickly find solutions to the things in their own environment that require those movements. You can have someone open and set out a couple of bottles of water and put a coffee cup down onto the kitchen counter for you. You can request some easy-open lids from the pharmacy for your pill bottles, and you can buy your milk in half gallon cartons. If you have small children, one of the hardest parts of your sternal precautions will be not picking them up or bending over to hug them or talk to them. You may want to talk to your children and explain in simple terms about your “boo-boo” and that it will only be a few weeks until you can pick them up again. You may find that you have an opportunity

to spend more quality time with your children. You can ask your children to join you on the sofa or sit on your lap while you watch a TV show together or read a story. You can sit with your children at a table and color with them, work a puzzle, or play a game.

“I found a firm teddy bear worked well for me. Each time I used it, I got a “bear hug”...the bear’s torso fit against my sternum, its arms fit over my shoulders, and its legs fit around my waist.”

You probably got used to holding a pillow to your chest when you were getting out of bed while you were in the hospital. You will probably want to continue that practice for a while at home. You can hold a firm pillow, a stuffed animal, or a pillow pet against your chest when you stand up from sitting on the sofa or in a chair. It not only helps to stabilize the sternum, it keeps you from pushing yourself up and it helps to control the pain.

Within a few days to a week or two of arriving home from the hospital, you will begin to feel stronger and more like yourself. As you get stronger, you will be able to start doing more things. Depending on your doctor’s instructions, you may be able to begin to do some light housekeeping chores such as setting the table, washing the dishes, and dusting. But don’t forget about your sternal precautions. You should not be doing things like mopping or vacuuming, lifting a laundry basket full of clothes, or bending over into the washer to get the clothes out. You will also feel like walking more and staying out a little longer on your outings. Be careful to not overdo it. It is important to set limits with yourself and with others, when needed. Listen to your body and realize that it is OK to say “no” when you are tired.

Remember, even though you are beginning to feel better, your body is still healing.

Emotional Recovery

You may find that your emotions are out of whack. It is normal to be emotional, have mood swings, and even be a little depressed during the first few weeks after surgery. You may feel discouraged with the pace of your recovery. But it just takes time. You should begin to feel more like yourself as your body heals and gets stronger. If your mood swings persist after two to four weeks or you are still feeling depressed, reach out to your doctor and let him or her know how you are feeling. In the meantime, here are some things that you can do to help get your emotions back in check:

“The first few days after getting home from the hospital, I would find myself sitting on the sofa crying and I wouldn’t even know why I was crying.”

- Talk to someone you trust about your feelings. It can help minimize the chances of long-term depression or anxiety.
- Go to bed at the same time each night. Getting plenty of rest will allow your body to refuel.
- Get up at the same time each morning and get dressed every day. Lying around in your pajamas all day every day can make you feel like you are “sick.”

- Open the curtains or window blinds in your home every day so the sun can shine in and you can see out. Find a sunny spot in your home to sit. The sunshine can help you to feel more cheerful.
- Enjoy the outdoors by taking your walks outside when possible.
- Do something relaxing that you enjoy every day (read a book, watch a movie, listen to some music, meditate, etc.).
- Have someone take you on little outings. The outings should be short and simple at first because you will get tired very quickly. As you gain strength, you will feel like being out for longer periods of time.

Returning to “Normal” Life Before Post-Surgery Restrictions End

Section author: Amy F-B.

The time when you are a few weeks past your immediate homecoming but are still on medical restrictions may be very frustrating. By now, you have likely weaned off the prescription medications and are starting to sleep a little bit better. You are likely to feel better and stronger. Depending on how symptomatic you were feeling prior to your surgery, you may already feel so much better than you did before surgery! You may be anxious for life to get back to normal. But, you still have these restrictions, and you will be doing many “firsts” after your surgery, causing you some tiredness, pain, and anxiety.

- You may be cleared to drive while you are still on restrictions. Before you get in the car, work on stretching your neck. Your neck muscles can tighten during your recovery process, and it can be painful to look to merge onto highways or to change lanes. You should be very comfortable with the motions of driving and not have any sense that you will hesitate behind the wheel because of a fear of pain. Start with short trips to assess your tolerance before going on longer drives.
- Consider the demands of your job when thinking of returning to work. In hindsight, many people wish they took more time off than they did. Even if you are feeling good, getting back into a routine of working for eight hours can be exhausting. If possible, consider returning on a part-time basis for the first week or two of your return. Working from home is also a good way to ease back into the routine if your job allows. Also consider how your job may affect other parts of your body. Sitting at a desk for eight hours may aggravate back or neck pain. Jobs that involve physical labor may need additional time off.
- Your immune system can also be weakened from your surgery. While you may want to resume your social schedule to feel more human, do so carefully. Stay away from people who are obviously sick. If possible, avoid large crowds. Use common sense, and wash your hands frequently.
- Keep using the spirometer if you’ve been directed to by your doctor. Some patients may need to go back on diuretics because fluid can still settle in your lungs if you aren’t using the spirometer or walking.
- You may have already ditched your wedge or recliner and have started sleeping lying flat in bed again. Congrats on that achievement! However, be prepared for some pain as you move or roll over in bed.
- Anxiety can be a normal part of returning to work, returning to drive, or doing some of the other activities that you couldn’t while on restrictions or before surgery. Try to pinpoint exactly what the anxiety is about and decide if it is realistic. Journaling can help. Talking

to other CHD patients can help. ACHA has many resources to help you and can put you in touch with an [ACHA Heart to Heart Peer Mentor](#) for support. Reaching out to a counselor can also help you process anxiety related to returning to activities and anxiety of the overall surgery and recovery experience.

- Accepting help is hard when you feel good. It's easy to be frustrated and angry. Be patient with yourself, and be patient with those who are trying to help you.
- Be careful not to do too much too soon. Many patients have reported setbacks to their recovery due to "overdoing it." Unfortunately, there is no way to know if you are overdoing it before you experience pain or a setback. If you need some guidelines, try to increase your activity by 10% per week. If that seems to be too much, try to only increase by 5%.



From the Heart of Tina

After surgery, I was referred to the cardiac rehabilitation program. I declined, thinking that since I worked in the medical field for a living, I could do my own rehab at home. I had all the right equipment, the knowledge and I was very determined to get back on my feet as fast as possible. And I did just that. Every morning I was up walking on the treadmill—slow at first, but then gradually I was able to push myself a bit more each day. In hindsight, however, I wish I had not tried to do this on my own. Cardiac rehabilitation is so much more than just an exercise program. It is a multidisciplinary program, encompassing not just exercise, but nutrition, weight management, education, psychosocial help, stress management, health coaching and sometimes even support groups. Just the social aspect alone of getting out of the house and around other people going through similar experiences would have been invaluable. Now that I work in cardiac rehabilitation (two years after I had surgery), I watch others go through the program and realize what a truly profound difference it makes in their lives. We can't always do everything on our own (a lesson I learned the hard way after surgery). Sometimes, it is better if we don't.



From the Heart of Amy

After I began lying in bed, I had trouble rolling over from side to side without pain. One night in particular, I made it from my right side to my back but the movement needed to get from my back to either side caused a significant amount of pain. I was uncomfortable on my back but in too much pain to make it to either side—I was stuck! I felt like I turtle flipped on its shell. My mom had to get out of bed to turn me on my side. I was also incredibly frustrated that I still needed so much help at this stage. Unfortunately, I took this frustration out on my family—the very people I needed help from. In retrospect, I wish that I had taken some time to be alone with my thoughts through journaling, speaking with a CHD friend, or speaking with a counselor to process my frustrations and fears. In addition, I wish I was more patient with my family. I was frustrated by the way my family helped me complete specific tasks because they weren't the way that I normally did them. Some of it was silly—like going in the "wrong" door at the supermarket. Some of it was more serious, such as preparing food that was unhealthy. Part of the frustration was being out of control, but I also wished that I had spoken up and expressed my thoughts instead of being angry that I still needed their help.

Immediately Beyond Post-Surgery Restrictions

Section Author: Amy F-B.

You are off restrictions! Congratulations! You can go out and do everything exactly as you did it before surgery, right?! Not exactly. You are still healing. If you had your breastbone cut open, the bones may be fused back together, but your chest muscles are not yet healed from the trauma of being cut. They are still inflamed and healing. Inflammation can take up to 12 months to heal. The nerve endings may take longer to heal. This time frame is another time that can be incredibly frustrating because you may feel as though life *should* be back to normal now. Being patient with yourself as you continue to heal and build your strength and stamina back will be critically important to finding your “new normal.”

- Developing a stretching and strength building plan is very important. If your cardiologist or surgeon did not recommend cardiac rehabilitation for you, your primary care physician may be willing to provide a prescription for physical therapy to help you rehabilitate your muscles and gain endurance. If your physician didn't recommend cardiac rehab and you are interested, ask for it. You may need to advocate for yourself to get a prescription for cardiac rehab if you want to go. For some patients, it made a huge difference in their recovery.
- If you cannot participate in a medically supervised physical therapy program, go slow and increase your activity over time. You may continue to experience pain, though it should lessen as months go on. If you need some sort of structure, consider increasing your activities and weight bearing by 10% each week if there is no pain. Remember that common household chores that you haven't been able to do in several weeks, such as carrying a gallon of milk, taking the trash out, pushing the grocery cart, and vacuuming, also count towards slowly increasing your activity over time.
- Some pain may be from your internal scar tissue tightening. Stretching will help keep the internal scar tissue from getting tight and causing pain during routine activities. Try to maintain good posture as well. See our section on [Exercise: Pre- and Post-Surgery to Enhance Your Recovery](#) for more guidance.
- You may also experience back and neck pain. Stretching these muscles and slowly strengthening your muscles may be helpful.
- You haven't used your muscles in several weeks. You will need to build your muscles up again. Weightlifting—starting with light weights—may help strengthen your muscles to their pre-surgery capabilities.

- Sometimes you don't feel pain until one or two days after exercising. Keeping a written record of your activities and what your pain level is in the following days can help you figure out if you are advancing too quickly.
- Rain and cold temperatures may cause soreness and pain. Recognize that your soreness on rainy or cold days may not be related to your activity levels. However, doing less activity on these days may make your day less painful.
- As you begin your exercise routine, rest days become very important. Your muscles will become irritated easily, and it is important to give them more rest than you would have before surgery in order to allow them to heal from both your surgery and your exercise activities.
- Women may experience additional discomfort in their chest from their breasts, even during low-impact activities or activities that are primarily lower body activities (like walking) that may cause your breasts to bounce. You may want a more supportive sports bra when you begin higher impact activities. The Moving Comfort® brand is often recommended. If you are experiencing discomfort from your breasts pulling on your chest muscles, consider sleeping in your post-surgical or a low-impact sports bra to help prevent your breasts from pulling on your muscles while you sleep.
- Check with your surgeon before using any creams, lotions, or injections mentioned in this section. Some surgeons do not feel comfortable recommending these products to their patients. Keeping your scar hydrated can help minimize its appearance as it heals. Vitamin E lotion and Mederma® are both available at many drug stores. Some patients have also found silicone scar patches to be effective and are available in drug stores or online. The dermatologist can also inject steroids into the scar to make it flatter. Make sure the incision is completely healed over before applying these agents. Note that some patients have found Mederma® has stained their clothes.
- Some cardiac patients report some feelings of depression or anxiety at this point. If you feel like you may have some depression or anxiety, we recommend talking to a trusted friend or relative and making your doctor aware. If it persists for more than two weeks, we recommend seeking assistance from a mental health professional. The sooner you address your symptoms, the less likely they will turn into a long-term issue.



From the Heart of Amy

After eight weeks of sitting around watching TV and reading, I was excited to get back to normal life. I wanted to jump back in to my daily routine with both feet. I live alone, and my mom, who lived with me for the eight weeks I was on restrictions, moved home. My dog, who lived with my dad while I was on restrictions, moved back home! Overnight, I was 100% responsible for all of the household chores and caring for my dog, who needed water, food, and to be walked and picked up after. All the bending down, taking out the trash, putting dishes in the dishwasher, vacuuming, etc. became very painful very quickly. I also started my pre-surgery exercise routine—including kickboxing and running—about 10 weeks after surgery. Yes, I was kickboxing 10 weeks after surgery!

By about two months after my restrictions were lifted (four months after surgery), I was in more pain than I was in during the immediate few weeks after surgery. By three months after restrictions being lifted (five months after surgery), I wanted to start taking narcotics daily. Finally, around four months after restrictions being lifted (six months after surgery), I spoke to my primary doctor, and she said that I may no longer be a surgical patient and my sternum might be healed, but the “rest of your body is still a mess!” I soon spoke with a friend who is an occupational therapist and her husband who is a physical therapist. They put together a stretching program for me that included NO aerobic or strengthening exercises for two weeks and a series of five chest stretches that I was to do three times a day for two weeks. After those two weeks, I could start strength building slowly and low-impact activities. I also hired family to do specific household chores that aggravated my chest (vacuuming, taking the trash out, pushing the grocery cart) so that I could spend my activities exercising. After the first day of following my friend’s strengthening program, I started to feel improvement! I can’t stress how important it is to stretch but also be patient and kind to yourself. I learned to let the clean dishes sit in the dishwasher for an extra day or two if I was sore or it if it was raining. It took almost 9-10 months before I could bend down to pick something off the floor and vacuum my house. I strongly feel that had I begun stretching routinely and eased more into exercise and household chores that I would have recovered faster than I did by jumping into everything at once.

Long-Term Recovery

Section Author: Amy F-B.

You are now a few months out from surgery. Hopefully, life is returning to normal. You might still be experiencing pain. Depending on how symptomatic you were before surgery, you might still feel a little more tired than you did before surgery. While some patients feel much better after three to six months, many patients report not feeling their energy return to their pre-surgery levels until one year after their surgery. Some patients who were very tired before surgery report feeling an additional boost in their new energy levels approximately one year after their surgery. Inflammation can take up to 12 months to heal. The nerve endings may take longer to heal.

- Continue to ask for help as needed. Some patients may need help with some household activities, such as vacuuming, taking the trash out, or picking things up from the floor for several months after being off post-surgical restrictions.
- Keep your scar covered with either clothing or suntan lotion for one year to avoid permanent changes to the coloring of your scar (making it darker).
- Scars can keloid and still appear pink for several months or even a few years. Some things that help are Mederma®, silicone patches, vitamin E lotion, and steroid injections from a dermatologist. The dermatologist injections work best within one year of surgery. The injections can be extremely painful, but they can eliminate itchiness, pain, and some redness. However, consult your surgeon before using *any* topical or injectable treatments. Some surgeons are not comfortable recommending these treatments for their patients.
- If it has been a long time between surgeries, your previous scars may have been invisible to most people. This new scar may be very pink and very noticeable. Even if you have never been uncomfortable about showing an older scar, realize your new scar will look different. You may feel differently about showing your new scar. If you decide you are not, mock camisoles can be great to use with V-neck shirts. Scarves can also be great to cover your scar. A little foundation or concealer can also minimize the color. Applying make-up to the scar should wait until the incision is fully healed; ask your doctor when you can begin to apply creams, lotions, or make-up.
- Eating healthy and exercising are also very important to long-term recovery. Your energy levels will continue to improve with a balanced diet and exercise—within your capacity and after checking with your doctor.
- Being patient with and kind to yourself continues to be extremely important. You may find little nuances of your body—some that seem unrelated to your heart—that are different than before surgery. These vary widely among patients, and many are minor and not visible to the outside world, but do not hesitate to speak to your cardiologist or another doctor about them.



From the Heart of Amy

Because I didn't start stretching and jumped into too many high-impact activities too quickly, it took until 9-10 months after surgery before I could bend down to pick something up off the floor or vacuum without experiencing soreness or pressure in my chest. At two years after surgery, I still feel some sharp pains in my scar or general chest achiness on rainy days or days where the temperature is below freezing. My cardiologist assures me these pains are normal, and my nerve endings are still healing.

I was extremely tired before surgery, so I felt a significant increase in energy very quickly after surgery. However, I did experience about a 15% increase in energy again about 13 months after my surgery. I tell people it took about a year to fully recover from open heart surgery.

A few examples of the nuances I've experienced are a seemingly permanent change in the heaviness of my periods, and my breasts seem to be facing diagonally instead of straight (when not wearing a bra).

My scar remained exactly the same from approximately six weeks after surgery (when it closed) to one year after surgery. It was bright magenta and raised. I was at the dermatologist for a routine mole check, and she mentioned that it wasn't likely to lighten or flatten on its own since it hadn't already. I began a series of four appointments of steroid injections that were four weeks apart. The itchiness disappeared immediately, and over time, my scar did begin to flatten. The overall color started to decrease as well. However, the steroid does spread out through the scar, so the color deepened in the spaces where my internal sutures were. The dermatologist assured me these areas would lighten in about a year, and they have. When we noticed the suture marks deepening in color, the dermatologist suggested that I may not see any additional benefit from the injections and suggested laser treatments. I declined the laser treatments. Now, two years after surgery, my scar is much lighter than it was at the one-year mark.

However, I still feel it is noticeable and have become extremely self-conscious about showing it outside of close friends and family. Part of me wishes that I had invested in the laser treatments because most shirts do show at least the top of my scar. I use a little bit of makeup to cover it when I feel the need to conceal it.

Preparing Friends, Family and Children

Section Author: Cassandra B.

Explain to your family and friends that you may be under a tremendous amount of stress and experiencing many emotions. Family members will also have their own emotions to process and cope with. It is important to remember that everyone deals with stress in different ways. If emotions begin to get in the way of your health or create tension in your day-to-day life, consider speaking with your surgical team. See if the hospital offers psychosocial services or can refer you to a mental health professional or a peer support program. Speaking with a professional about can be a tremendous help.

Preparing your children for upcoming surgery/procedure

Discussing the limited activity that you might have with small children is very important. You may want to explain how you may not be able to play the same for a while, and there may be an increase in movie times. If possible, allowing children to stay at a relative's house during the initial homecoming may be beneficial. Upcoming events should be explained to the children in age-appropriate ways. For instance, what you would tell a six year old would be very different from what to tell a 16 year old. It is extremely important that the children know that you are in good care and they will be in good care also while you are away.

It is important to remember that children are resilient. With proper preparation and support, they will be able to get through the stress of this. Without the preparation and support, they can be emotionally scarred—even if the parent recovers quickly and fully.

If the hospital allows children to visit, children should be given an option to visit or not visit, depending on their comfort level. If they choose not to visit, give them an alternative to the visit, for example, sending a picture, picking some flowers, or writing a letter someone can bring to the hospital. Remember the visit should be about the child's comfort, so do not force a child to visit in a way they are not comfortable. This is his or her opportunity to see you and process what is happening. The child may want to meet your physician and/or nurses who are caring for you—if possible, make arrangements for this to happen.

If you are in critical care, keep visits brief. If the visit is during a non-critical time, consider bringing games or other activities you can do together as a family; if you are up for it, you can suggest they bring their homework or other age appropriate activity to do at bedside.

Discussing upcoming surgery with co-workers

Some people are comfortable giving co-workers the details of their heart condition and surgery. Other people wish to keep the details private. If you choose to keep the details private, you may not want to specify what type of surgery you will be having, but disclose you are having surgery

and will be out for the recommended amount of time. Depending on your type of job, mention that you may not be 100% when you return.

Friend and Family Visits

- Be honest with family and friends. You may not want visits for a time right after returning from the hospital.
- Understand friends and family want to make sure you are recovering well.
- Communicate. If you do not feel up to it, have a family member or friend update social media, email, or send a group text with your recovery status.
- Set a time for visits. Visiting hours happen in the hospital for a reason. Consider setting up your own hours and have a family member or friend be in charge of enforcing these visiting times.

Ask for help. Many people have trouble asking for help. However, numerous studies have linked having friends and family come around during a time of recovery to the speed at which an individual recovers from surgery. Assembling a team of trusted individuals to take on needed responsibilities, such as organizing meals, doing laundry, cleaning, child care, carpooling, and visits can enable you as the patient to focus on recovery. Many family and friends are willing to help but don't know what to do. Do not hesitate to ask for a specific task to be done even if it is not something you typically would allow other people to do.

If you are the primary chef in the household, have friends and family bring meals. Many families assemble a schedule for family and friends to provide meals. Another option is to hire a catering company to deliver meals. HomeBistro.com and ArtikoChef.com are two suggestions, but there are many others. Remember to check with your doctor if you will have dietary restrictions after surgery.

Set up appointments with a maid service to clean during recovery, or if a friend or family member volunteers allow them to help with cleaning

Depending upon procedure/surgery, exercise may be crucial to recovery. Have a friend or family member exercise with you. This enables visits as well as encouragement for recovery.

Each person in the family may react differently to the news, and some may be unable to be that source of support for you. If you are usually the “emotionally strong” one in the relationship, he or she may unintentionally come to you for your support. It is important that if this happens, you gauge yourself and your comfort level on this. If it is interfering with your ability to adequately prepare yourself, then you need to speak up and set some limits. Ask another family member for help, if needed. Sometimes a caregiver support group or online support can be helpful to the family member or friend and to you.

When the patient becomes the supporter, our brains transition into a job mode rather than survival mode, which can give us a sense of purpose rather than focusing on the surgery and recovery. It can also bring into focus that I, as the patient, need to survive this for them. Even though most patients with congenital heart disease have lived with their diagnosis for their whole lives, it does not make them immune to the emotion surrounding a medical crisis or surgery. For some patients,

the more they go through invasive procedures, the more difficult it is to deal with emotionally. It is imperative that you find at least one person who will support YOU unconditionally.

Going through a medically-related crisis can strengthen relationships, but if not handled delicately, this experience can also negatively impact even the closest of relationships. That is why it is important that the lines of communication remain open, your boundaries are enforced, and that an overall sense of respect is maintained. You should never be afraid to ask for help for support. Often, getting guidance from a trusted family member, friend or qualified mental health professional can make all the difference in the world.



From the Heart of Cassandra

I believe that you don't need to share more than you are comfortable sharing. The amount of information you give at work depends on your relationship with the organization and with the individuals you work with. Many patients, me included, gave only the necessary information to their supervisor and were careful who to give additional, more personal information to.

Asking for help is something that I struggle with a lot. This probably stems from knowing that my recovery is mine and mine alone. It is between me and my body. However, accepting help allows for my recovery to progress much faster than if I were to try and do everything on my own. For example, after my fourth open heart surgery, one thing that was not taken into account was being able to get out of bed to go to the restroom. Having someone to help you get out of bed during the night may sound like a difficult request; however, depending on your restrictions and level of pain, if you try and do it by yourself, you may end up injuring yourself, thus prolonging your recovery.

Being around groups of people was very hard to handle shortly after major procedures/surgeries. This may take experimentation to determine your level of group numbers you are comfortable with after major procedures/surgeries. I, personally, had difficulties with groups of four or more. Everyone deals with stress differently. If we are mindful of this fact, then it allows us giving the other person the benefit of the doubt. It also allows us to understand what may be going on in the other person's head during this stressful time.

For example, my dad, during all of my major surgeries, was never at the hospital and avoided me as much as possible during my last open heart surgery. I know that he is not one for hospitals or seeing people in pain and so his solution is avoidance. However, once I was on the mend then our relationship was back to "normal." It was not an easy time, but I was fortunate enough to have my brother and friends who supported me during my initial recovery time. I think it is also important that you remember you cannot change anyone. You can gently state your needs but if a loved one isn't comfortable with certain situations then you may need to evaluate if there is someone else who can be there for you instead. Perhaps there is another role they can fill to support you that they are more comfortable with?

Exercise: Pre- and Post-Surgery to Enhance your Recovery

Section Author: Melissa H.

The news has come. It is time for you to have heart surgery. Research shows that you can significantly enhance your recovery if you incorporate the proper exercise before and after your surgery. “Exercise may be used as a means to improve (surgery) outcomes. By maintaining or increasing muscle strength and flexibility, cardiorespiratory fitness, and neuromuscular control, the patient may be better prepared to continue the rehabilitation program after surgery.”¹⁴

Prior to surgery, you want to be as healthy as you can be. In order to accomplish that, you want to engage in the proper exercises for you. Clarify with your doctor what your restrictions are before adding any activity, especially resistance training. While most activity is beneficial, heavy resistance training may need to be avoided by some people.

There is much evidence to support that adding physical activity to your daily routine will benefit your overall health. According to the 2013 Canadian Cardiovascular Society Heart failure management guidelines update, “All patients with stable symptoms should be considered for enrollment in a tailored exercise training program to improve exercise tolerance and quality of life.”¹⁵

One study found that patients such as yourself who “participate in a moderate-intensity combined aerobic and resistance exercise program may improve performance of routine physical activities of daily living by using a home-based exercise approach.”¹⁶

Based on the above statements, this section will address simple ways you can incorporate specific exercises to help you prepare for and recover from your surgery.

This section of the book is divided up into pre-surgery exercises and post-surgery exercises. There are two different goals patients should strive to achieve. Prior to surgery, you will want to focus on increasing strength and after surgery the focus should be on regaining your range of motion (ROM).

¹⁴ Prentice, W. Principles of Athletic Training A Competency- Based Approach. McGraw-Hill. 2011. 422.

¹⁵ Moe, G, Ezekowitz et al. Society Guidelines: The 2013 Canadian Cardiovascular Society Heart Failure Management Guidelines Update: Focus on Rehabilitation and Exercise and Surgery Coronary Revascularization. *Canadian Journal of Cardiology*. 2014: 30(3):249-263.

¹⁶ Gary, R, Cress, M, Combined Aerobic and Resistance Exercise Program Improves Task Performance in Patients with Heart Failure. *Archives of Physical Medicine and Rehabilitation*. 2011; 92 (9): 1371-1381.

Pre-Surgery

One exercise you will want to incorporate is the squat. It is important to remember that you squat every day when you sit down and get up from a chair. After surgery, you will rely heavily on your lower body. Get it ready. In the hospital, the first time you get out of bed without assistance may be challenging. Start teaching your body the movement early. As you perform the movement, tell your body what to do, “Push the floor away,” “Push the heels into the floor,” and “Straighten your knees and hips.” These are all examples of things you can say to help cue your body to the proper movement. Remember, movement relies on both the muscles and the nerves. If you experience knee pain, your form is incorrect. Be sure to bend at the hips first and keep your weight in the heels.

1. Squat



1. Start with your feet about shoulder width apart, or a bit wider is ok.
2. Keeping your weight in your heels, sit your hips back like you are sitting in a chair. Keep your knees wide over your toes at all time and your weight in your heels. Keep the arch in your foot. Your hips should move first and your knees should not travel forward of your feet as you descend. If you experience discomfort in your knees, check your form or do not squat as low.
3. Squat only as low as you are comfortable going, but go as low as you can. Hold it for a count of 3. Slowly return to a standing position. Repeat for 12-15 repetitions. Do 2-3 sets as tolerated. If you are able, add weights to this movement. You can hold dumbbells at your side or a weight at your chest.

2. Bent Over Row

Many people have some discomfort in their upper back after surgery. The “Bent Over Row” can help to decrease that possibility and minimize the discomfort. If you do not have any dumbbells, you can use anything with a bit of weight (such as water bottles or half-gallon jug, cans of food, plastic bottles of ketchup or salad dressing). Use as much weight as you can and still get 15 repetitions.



Notice the starting and ending position of the shoulder blades:



1. Start with a slight bend in your hips. Knees should be slightly bent and abs drawn in to protect your back. Arms hang in front of you with palms facing up or toward each other.
2. Bending your elbows, pull from your shoulder blades as you bring your arms out even with your body.
3. Hold for a count of 3 and slowly lower to the starting position.

Any other resistance training exercises that you like to do and are approved by your doctor may be added to this routine. These are just a few suggestions to incorporate to help prepare you for surgery.

Cardiovascular recommendations

For adults, the minimum recommendation for cardiovascular activity from the American College of Sports Medicine is 30 minutes of moderate activity (like walking) for five days each week or 150 minutes each week. Keep your intensity comfortable—at a pace where you can still have a conversation but are breathing harder than if you were at rest. According to the U.S. Department of Health and Human Services physical activity guidelines for 2008, “Regular participation in physical activity results in many health benefits for those with chronic health conditions.”¹⁷ If you are unable to get in the 30 minutes at one time, do shorter frequent bouts as much as you can.

These guidelines also recommend seeking supervision about types of activity from your doctor.

¹⁷ 2008 Physical Activity Guidelines for Americans. President's Council On Physical Fitness & Sports Research Digest. December 2008;9(4):1-8.

Post-surgery

Proper levels of activity and exercise will enhance your recovery, help you regain complete movement of your arms and upper body, and decrease pain in the chest, shoulders, upper and lower back. In addition, activity will increase blood flow to the heart and lungs.

The first goal is to decrease pain and to get your range of motion back. As always, consult with your doctor for specific recommendations for you. Everyone is different. These exercises are divided up into two levels. Level 1 is one arm, and Level 2 is both arms.

Week 1: Once you get home from the hospital, you may still have pain, which will limit your physical ability. At this stage, use pain as your guide. When you are ready, as indicated by your level of pain and the time limit placed by your doctor, the Level 1 exercises may be started, as tolerated 3-5 times a day, in sets of 5. Always keep your motion within pain-free limits. If you get tired or short of breath, or if you have any pain in the chest, stop exercise for that session.

At this point, your cardiovascular activity should be light, such as walking around your house, maybe up and down your driveway for 3- 5 minutes at a time, 3-5 times a day. You may want to stretch your legs, but your upper body may not be ready.

Activities of daily living should be as tolerated by pain. Do not lift more than told by your doctor or nurse. Getting things out of the oven or getting laundry out of the washer are not possible. In the beginning, even opening the refrigerator door can be a challenge. If you need to pick something up off the floor, try to squat down with your weight in your heels. If you are not ready, it is important to ask for help from family or friends.

Week 2: Continue to do range of motion exercises from Level 1 until you can get complete motion. It is important to remember to use pain as your guide. As you continue to do the exercises, your range of motion should increase. At this point you may be able to get 810 reps, 3 sets, 2-3 times per day.

In terms of your cardiovascular activity, continue as prescribed by your doctor. If you were not given any direction, do what you are comfortable doing and gradually increase your time and frequency. Avoid increasing intensity until you are in cardiac rehabilitation or are told to do so by your doctor. Gradually increasing the duration and frequency as your doctor approves. For example, if once a day is easy, try doing your exercises two times a day.

You may notice that activities of daily living will become easier. You will still need to squat down to get things off the floor. Bending over might still be painful. You may be able to put dishes or other things away if you do so one at a time and with one arm at a time. If possible, allow family and friends to continue to help you. If possible, try scheduling a cleaning service for your first few weeks home. Using both arms may still be painful for three or four more weeks.

Weeks 3-5: As you get into Week 4, typically pain will start to decrease. Continue with your range of motion exercises. As you get closer to Week 5, you may be able to move both arms overhead without pain. Again, check with your doctor for specific recommendations. There is no agreed upon date for lifting both arms over head, and this should be specific to you and what your doctor recommends.¹⁸ Once you can lift both arms overhead, proceed to Level 2 of the exercises. You may want to add a 2-3 pound dumbbell or a Thera-Band to your routine. Let pain be your guide. If it hurts, do not do it.

Cardiovascular activity may be better tolerated. Some examples of places to walk when the weather is bad are the grocery store aisles or the mall. Try to get up to 20 minutes of light activity.

The following are suggestions of range of motion exercise that will help you and should be easy enough for most people. If you are having difficulty, seek help from your nurse, physical therapist, or doctor.

Post-surgery exercises

Level 1 exercise are all with one arm only, and Level 2 is bilateral (both arms)

1. Shoulder Forward Flexion (lifting forward)



1. Start sitting or standing. Face front.
2. Align your ears with your shoulders, looking from the side as in picture 2, so your head is not sticking out forward of your body. Slowly raise your arm out in front of you as high as you can.
3. Hold for a count of 3. Slowly return to the beginning. Repeat on the other side. Perform 5 repetitions for 3 sets 3 times a day. Increase to 10 repetitions when ready.

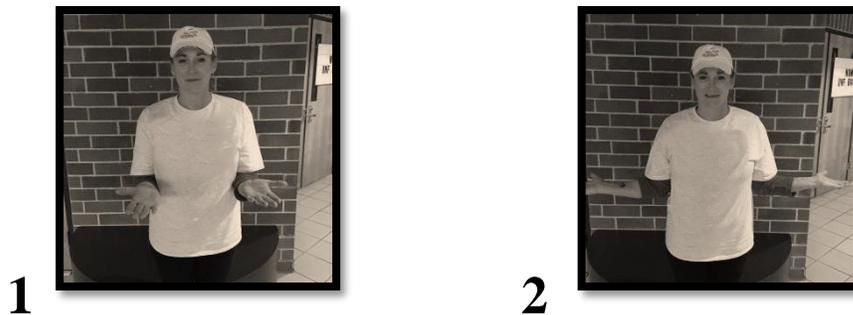
¹⁸ Cahalin, L. Sternal Precautions: Is it Time for Change? Precautions versus Restrictions- A Review of the Literature and Recommendations for Revision. *Cardiopulmonary Physical Therapy Journal*. 2011(22) 5-15

2. Shoulder Abduction (lifting sideways)



1. Start seated or standing with your arms by your side.
2. Slowly raise your arm out to your side as far as you can without pain.
3. Hold your arm as high as you can for a 3-second count and slowly lower to your side.

3. Shoulder External Rotation (like hitchhiking)



1. Start facing front with your arms bent and palms up or facing each other.
2. Keeping your elbow locked at your side, bring your hand out like a hitchhiker. Be sure to pull that same side shoulder blade toward your spine as you move your arm. You can do this exercise with or without weights.

4. Shoulder Shrugs with Scapular Retraction (bring shoulder blades together)



1. Start seated or standing.
2. Pull one shoulder up toward your ear and slightly back at a diagonal.
3. Hold for a count of 3 and slowly return to the starting position. Repeat 5 times for 3 sets. Gradually work up to 10 repetitions.

5. Neck Lateral Flexion (bending side to side)



1. Stare straight ahead making sure looking from the side that your ears are in line with your shoulders. In other words, your head is not sitting forward of your shoulders. (As in post-surgery exercise 1)
2. Slowly lower your right ear to your right shoulder as far as you can without pain.
3. Slowly return to the center and repeat on the left side. Do 5 repetitions of 3 sets, 3 times a day. Work up to 10 repetitions.

6. Neck Rotation (looking side to side)



1. Start facing forward with your ears in line with your shoulders, as in exercise 5.
2. Slowly look to your left as far as you can without pain. Hold for a count of 3
3. Slowly look back to the front.
4. Repeat to the right side. Do 5 repetitions, 3 sets, 3 times a day. Progress to 10 repetitions.

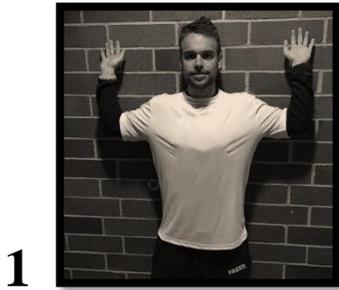
7. Posture Training

Stand with your feet, hips, shoulders and head touching the wall. Try to have your body, including your back and head, touching the wall. As you progress, try to bring an arm up beside you with your elbow and back of your hand touching the wall.

Level 2

After approximately five weeks, you may be able to progress to Level 2 if you are cleared to lift both arms above your head. This level includes adding two arms to the exercises above so you are moving both sides at once.

Use a wall to do this exercise. You may find this exercise difficult. Only progress as far as you can without pain.



1. Stand with your feet, hips, shoulders and head touching the wall. Lift your arms up so that the backs of your hands and your elbows are touching the wall. Your hands should be about as high as your head.
2. Slowly, keeping your hands and arms in contact with the wall, raise your hands over your head as far as you can without pain. Hold for a count of 3. Lower to your starting position. Repeat 5 times for 3 sets. Gradually increase your reps until you get to 10.

After Weeks 8-10, you may be ready for a cardiopulmonary rehabilitation program. Check with your insurance, and ask your doctor for a referral. Keep exercising and staying in contact with ACHA!

A special thank you to our models! Both are CHDers with surgery and exercise experience. One has a ventricular septal defect and the other has tetralogy of Fallot.

Traveling for Surgery

Section Author: Deborah F-K.

Many congenital heart patients do not have adult congenital heart centers located close to home, and travel is often involved for annual checkups and open heart surgery. Any surgery is stressful; however, planning a trip on top of preparing for surgery can increase stress and anxiety. Fortunately, many congenital heart surgeries can be scheduled well in advance, giving you time to plan your trip to the location where you will have surgery and your trip home.

When you are finalizing the date for surgery, ask your surgeon when you will need to be in the area. You may need to arrive a day or two before surgery for any additional tests. As soon as you know the surgery date, book a hotel for your pre-surgery stay and for any family members accompanying you. Check with your hospital's patient information group—they can often provide you with a list of hotels offering discounted rates for patients and their families. Some hotels even offer free shuttle service to and from the hospital for family members. Make your reservation as soon as possible since often times there are only a limited number of rooms at the discounted rate. Obviously, you will not know the exact date of discharge or when you will be returning home. Advise the hotel staff of this, and they can most likely work with you to shorten or extend the reservation.

Also, as soon as you have your surgery date, be sure to check with your health insurance regarding any advance authorization required. This can be a lengthy process, particularly if your initial request is denied and you need to appeal. Make sure your authorization covers all aspects of the pre-surgery, surgery, and post-surgery care. Your hospital can help with this process. Take advantage of the fact that hospitals are usually familiar with insurance companies and frequently know the specific insurance codes for the exact procedure(s) you will be having. This can help the pre-approval process go quickly and correctly.

If you have pets you are planning to board, you should also make boarding arrangements when your surgery date is known. You should let the facility know that the exact return date is subject to change. Particularly if you have an active dog (as I do!), you may want to consider boarding him or her one or two days before you leave and one or two days after you get home. If you have never boarded your pet at the facility, you may want to consider a visit or tour with your pet beforehand—particularly for dogs. An alternative to a boarding facility is to leave your pet with a trusted family member or friend who likes animals.

If a family member is accompanying you during the surgery, he or she may also be stressed and anxious as well. You will likely have many friends back home who will anxiously await updates as to your condition. Pick one person to be one point of contact to update everyone. You can set up a group email list, group text message, or social media page for your point of contact to update everyone at once.

You might also want to set up a support team for when you get home. You and your accompanying family member will be tired when you get home. Ask a friend or family member to have meals delivered for at least your first week home. Most people would be happy to help out—they only need to be asked!

Of course, do all the pre-trip tasks you usually do, such as stopping the newspaper and mail delivery. Ask someone to check on your house and to pick up any deliveries, should they be made. If you have any regularly scheduled services, you may want to cancel these until you return home.

If you will be traveling by air, the ACHA website has some excellent travel recommendations for the congenital heart patient. However, traveling after surgery has its special challenges. Once you have the date of surgery, make your flight reservations as soon as possible. If you cannot easily modify the reservation, you may want to consider just making it one-way until you know your discharge date. Be sure to check with your airline about any post-surgery flight requirements. Some airlines do have restrictions on how soon open heart surgery patients can travel, and some airlines also require a doctor's clearance.

Your surgeon will know that you are from out of the area and will not discharge you until you are “road ready.” Flexibility will be needed—your surgeon may recommend that you stay in town, but not in the hospital, for a few extra days, or may even recommend a brief stay in a rehabilitation facility. Most patients are scheduled for a post-operative visit with the surgeon a few days after discharge to check the incision, remove sutures, etc. Your discharge nurse can also make travel comfort recommendations—be sure to ask if it is not brought up. For example, it is recommended that when traveling by car, be sure to get out every one or two hours and walk around. Any pre-home planning that can be done is also helpful. For example, perhaps any prescriptions can be called in to your local pharmacy in advance so they will be ready when you arrive home. Proper planning will help make your pre- and post- surgery travel as worry and stress free as possible, enabling you to focus on your health and recovery.

Click [here](#) for ACHA's Travel Resources.

Advance Care Directive

Section Author: Anna T.

Do you have an Advance Care Directive? The most basic definition is a legal document (depending on where you live in the world) that explains your health-related wishes when you are unable to. You also are able to name a person, called a healthcare agent or healthcare proxy, who is able to make decisions for you when you can't or do not want to.

Living Will, Personal Directive, Advance Healthcare Directive, Healthcare Power of Attorney, Advance Decision, and Advance Directive are the different names it can be called in the United States, depending on what state you live in. If you live in a state that requires two documents, they are usually a Living Will and Healthcare Power of Attorney. A Living Will describes your healthcare wishes while Healthcare Power of Attorney names a person to make your decisions. If you live in a state that only requires one document, the document, usually called an Advance Directive, is a combination of the Living Will and Healthcare Power of Attorney.¹⁹

Finding out which document or documents you need to fill out is the first step. There are plenty of websites that will tell you which ones you need. Aging with Dignity has a [Five Wishes](#) document that is legally recognized in most states.²⁰ There is currently a fee of \$5. You put in your state, and it gives you the appropriate forms. There are eight states that are not covered by Five Wishes (Alabama, Indiana, Kansas, New Hampshire, Ohio, Oregon, Texas, and Utah). Five Wishes states that people from these states have used the forms as a guideline. It is very user friendly.

You can also contact your hospital. If you are contacting your hospital, the best place to start is the Patient Relations department. They will have the document or documents you need to fill out or can direct you to the correct department. If you are having surgery in a state other than where you live, contact the hospital you are having the surgery at and see if your current document(s) will be followed, or if you need to fill out different document(s) for that state.

Once you obtain the correct document(s) comes the hard part—deciding who you want to be your decision-maker (healthcare agent) and what decision you want made. When deciding on your healthcare agent, it is important to pick the right person for this task. Think about the types of decisions that will need to be made. Choose someone who will be able to carry out your wishes and choose the care that you would want.

¹⁹ What Health Care Directives Are Called in Your State. Available at: <http://www.nolo.com/legal-encyclopedia/health-care-declarations-your-state.html>. Accessed August 14, 2019.

²⁰ Five Wishes and You. *Aging With Dignity*. Available: <http://www.agingwithdignity.org>. Accessed August 14, 2019.

The healthcare agent will need to be able to make decisions under emotional distress. Your agent should be someone who knows you and understands your medical condition.

They to be knowledgeable about you so they can make appropriate choices. Your agent will have the responsibility of communicating with your healthcare team, family members and friends. They will also need to be able to come to the treatment facility. When choosing your agent, you might not want to choose someone that is out of state. There is a possibility for you to have a second healthcare agent if the first one is unable to make the decisions. All of the same things should be known to your back-up healthcare agent as your first.

When selecting a healthcare agent, some states have laws about who it cannot be. For example, members of your healthcare team or employees of the healthcare facility where you receive care may be ineligible.

When you have selected someone, talk with them. Let them know what your wishes are. Speak very openly with them so that when the time comes, there are no questions about what you want. The healthcare agent has the right to refuse or accept any care, treatment, service, or procedure on your behalf when you are unable to do so. They can also choose to release any doctor or facility.

Your healthcare agent will be the one discussing your condition with your healthcare team. When you pass away, your healthcare agent will make the decision on organ and tissue donation if you have not already consented to this and if an autopsy will be done. There are a few decisions that your healthcare maker is unable to make. They do not have the right to admit you to a mental health hospital. They are not able to consent to electroshock therapy, invasive psychiatric treatment, sterilization, or abortion.

Deciding what you want is a very personal choice. It is not always black and white. Life support can include several types of support. Life support is any medical device to help you breathe, CPR, medication, artificial nutrition and fluids given by a feeding tube, surgery, blood transfusion, dialysis, or anything else that is used to prolong your life. Most forms give you choices and space for very detailed instructions. You can choose what you want or don't want. Religion can also play a part in your Advance Directive, which is OK.

There is also a term called comfort care. Comfort care is when efforts are no longer focused on prolonging life but helping with managing symptoms. Comfort care can come into effect when your condition is not curable, and you no longer will have a good quality of life.

Your Advance Directive should state what you would want if you are pregnant. Whether the doctors honor your choices depends upon a few things, such as which trimester you are in. A pregnant woman may not be removed from life support if the fetus can develop to full term. Many states do have laws regarding pregnancy and life support. Know the laws in your state and/or the state in which you are having surgery so you can plan accordingly.

There are a few instances where a doctor or facility can reject your Advance Directive. As stated above, pregnancy is one of the rare instances where the law can override your wishes. There are a few others as well, such as if your wishes go against the conscience of a doctor or facility, if you

are receiving medically ineffective treatment, or if your wishes violate basic healthcare standards used by the doctor or hospital. Your Advance Directive won't be ignored. The doctor or facility must notify you and your healthcare agent if they cannot honor your Advance Directive. Then, they must take the steps to transfer you to a facility that will honor your wishes. Depending on the state, the facility or doctor can become legally responsible for damages.²¹

Now that you have filled out your Advance Directive, it is time to make it legal. Every state has different rules on how the document/s are made legal. No matter which state you live in, you will have to sign the document/s. Do not sign it until you are in the presence of your witnesses, a notary, or both, depending on state law. Some states have rules about who cannot be your witnesses. They will not allow any spouse, close relative, or any people who will inherit property. Your doctor or any personal or professional who has invested interest in you or has a conflict of interest is also not allowed to be a witness.

A notary is a person who is authorized by the state to verify signatures. They are found in many places, and you can search online or in the yellow pages. They may also be part of hospital staff. In some situations, some notaries may come to you. They watch you sign, and then they fill out a portion or attach a separate paper to your form, acknowledging that you are who you say you are. There may be small fee for this. Often, the notary at your attending hospital is free. You will also have to show a government issued photo identification to prove you are who you say you are.

Now that your document is filled out, signed and made legal, what do you do with it? Have family and close friends view it, so when it becomes active there are no surprises to your family or friends. There are a few key people who should have a copy of this document (a photocopy of your Advance Directive is just as legal as the original):

- Your healthcare agent
- Your doctor and your healthcare team

You should also take it with you if you go to the hospital or emergency room and keep the original in a safe place at home. Once you have finished with this last step, your Advance Directive is done.

If you change your mind about your wishes or your healthcare agent, destroy your old Advance Directive and all copies. Notify your healthcare agent that you are making changes or write void over them. Create a new Advance Directive following the same procedure as you did before. Have your witnesses or a notary sign it, depending upon the law. Give the new copies to your doctor and healthcare team. If you make significant changes, you might want to talk your family and friends again.

An Advance Directive is something that many people procrastinate completing. It is an important part, however, of caring for your body in a responsible way. Once you do it, you do not have to think about it anymore.

²¹ Advance Health Care Directive Kit. University of California, San Francisco. University of California, San Francisco Medical Center/ UCSF Benioff Children's Hospital.

Family and Medical Leave Act (FMLA Law)

Section Author: Diane N.

The resource for this section was the U.S. Department of Labor publication.²² Please visit the U.S. Department of Labor website for additional information.

If you work, you will need some time off from work for your surgery and recovery. If a family member (spouse, parent, or child) who will be caring for you also works, he or she may also need some time off from work. Both you and your family member may qualify for a Family and Medical Leave Act (FMLA) Leave. This law is designed to protect your job for up to 12 weeks in a 12-month period of time if you have a serious medical condition so you will not have to choose between your health and your job. It is also designed to protect the job of a family member if you need someone to care for you because of a serious medical condition.

A serious medical condition includes:

- Conditions that require an overnight stay in a hospital.
- Conditions where you are unable to work for at least three consecutive days and you require ongoing treatment (doctors' appointments or prescription medication).
- Chronic conditions that require treatment at least twice a year.
- Pregnancy (including morning sickness, doctors' appointments, and physician ordered bed rest).

An FMLA Leave provides the following benefits and protections to you and/or your family member:

- You will be able to take an unpaid leave for up to 12 weeks in a 12-month period.
- You may take your leave all at once or you may use it on periodically for things such as starting back to work part-time after surgery or going to cardiac rehab and doctor appointments.
- You will be able to return from your leave to your same job (or one that is similar with respect to duties, responsibilities, pay, and benefits). There is an exception for key employees (salaried employees that rank in the top 10% of the employer's highest paid employees within 75 miles). Key employees are not guaranteed that they can return to their same position.
- Your employer must continue your health insurance coverage while you are on an FMLA Leave (you will still have to pay your normal monthly premiums).

²²The Employee's Guide to the Family and Medical Leave Act. U.S. Department of Labor. Available at www.dol.gov/whd.

- An FMLA Leave is a protected leave. Your employer cannot retaliate against you for taking an FMLA Leave or use your leave against you in any way. This includes any disciplinary actions, strikes against you for attendance, or withholding raises and promotions.
- If your employer provides paid time off for vacation and sick leave and you have accumulated paid time off hours in those banks, you must be allowed to use your accumulated time. However, you must still follow your employer's normal paid time off policies. Employers have the right to mandate that you take paid leave. Check with your human resources organization,

In order for you and/or your family member to get these benefits and protections, you must each qualify for an FMLA Leave at your respective employers.

First, your employers must be considered "Covered Employers." In the public sector, all government agencies and the elementary and secondary schools are considered "Covered Employers." In the private sector, your employer will be considered a "Covered Employer" if it has 50 or more employees and at least 50 employees that work at either the same location as you or at other locations that are within 75 miles of your work location.

Second, you must be considered an "eligible employee." In order to be considered an "eligible employee," you must have at least 12 months of service with the employer. However, it does not need to be 12 consecutive months of service. If you had a break in service with the employer anytime within the previous seven years, then your previous service with that employer will also count towards the 12-month service requirement. Examples of a break in service are if you left your job and were later re-hired or if you perform seasonal work. In addition to the 12 months of service requirement, you must also have worked at least 1,250 hours during the previous 12 months. For this requirement, a break in service will only count if it has been within the previous 12 months.

You do not have to specifically ask your employer for an FMLA Leave, and you do not have to give your diagnosis to your employer. However, you do have to give your employer enough information for them to know that you will potentially qualify for an FMLA Leave. When possible, you must provide your employer with at least 30 days' notice that you need the time off of work. When it is not possible to give at least 30 days' notice, you should notify your employer as soon as you know you will need the leave time. If it is an emergency or something comes up unexpectedly and you are not able to give your employer an appropriate notice, follow your employer's usual call-in procedures when possible.

Your employer is required to notify you of your eligibility for an FMLA Leave within five business days. If your employer determines that you are not eligible for an FMLA Leave, the notification should state the reasons. Otherwise, the notification should include information regarding your

FMLA rights and responsibilities. Since you are eligible for up to 12 weeks of leave in a 12-month period, the notification should also include the employer's definition of the 12-month period. Some employers use a calendar year; others use the employee's anniversary year or the 12 months beginning with the first day of the leave time.

Your employer may ask you and/or your family member for a medical certification of your need for the leave. The certification should contain the following information:

- Your healthcare provider's contact information.
- When your serious medical condition began and how long it is expected to last.
- If your medical condition will require hospitalization, doctor visits, treatments, etc.
- If you are unable to work and if you will need a family member to assist in your care.
- If you will need your leave all at once or periodically.
- The medical necessity of the need for a leave periodically and how much time you will need each time you need to be off.

You will have certain responsibilities regarding your FMLA Leave. You must obtain the medical certification within 15 days if your employer has asked for one. You may have to pay your doctor a fee to fill out the certification form for you. If your employer notes any missing information in the medical certification, you will then have seven days in which to provide the needed information. Your employer can deny your FMLA Leave time if you fail to obtain the medical certification if requested or fail to provide additional information within the given timelines. Your employer may also ask you to get a second opinion and a third opinion when the first and second opinions differ from each other. You must comply with your employer's request to get the second and third opinions, but you do not have to pay for them. Your employer is required to pay for the second and third opinions.

You must communicate with your employer on a timely basis. Let your employer know of any changes in your need for FMLA Leave time as soon as you know you will need them. You may need to extend your FMLA Leave time past your initial request in the case of unforeseen issues such as with medication changes or you may need to use part of your FMLA Leave periodically.

You must be sure you follow the employer's FMLA Leave policies. Educate yourself on your employer's leave and paid time-off policies and make sure you understand them. Make sure you know things like what forms you might need to fill out, where you get the forms, if you will be required to use time from your paid time-off banks, who your employer contact is regarding your leave time, how you will be paying for your insurance premiums while you are off work, etc.

You must return to work by the end of your 12-week FMLA Leave in order to retain all of the protections that the law gives you. If you return by the end of the 12 weeks, you should get back your exact position or one that is close to the same. If it is not the exact position, the position you are given must be similar in the job duties, responsibilities, and status of the one you had before your FMLA Leave. The new position must require essentially the same skill set, level of authority, and general work schedule. It should be at the same work location or a location that is nearby. You should get the identical pay, including any opportunities for bonuses, commissions, overtime, or any other extra pay items that you were getting before your leave. You should also get the identical

benefit structure, including health insurance, life insurance, paid time off, sick leave, pension plan, and any other benefits that you had before your leave.

If you feel that you did not receive all of the protections that you should have received when you returned to work, that you were retaliated against, or that you were subjected to disciplinary action due to your FMLA Leave, you may file a complaint by contacting the U.S. Department of Labor Wage and Hour Division at 1-866-487-9243.

GLOSSARY OF TERMS

Anesthesia — medication provided to a patient during surgery so that a patient does not feel pain.

Advanced Directive/Living Will — legal documents stating your wishes for medical care in case you are not able to make decisions for yourself.

Bloodless Care Protocols — the practice of using only the patient's own blood during surgery.

Complementary medicine — treatment or preventive measure to help a patient's wellbeing together with traditional medicine.

Keloid — abnormal growth of scar tissue.

Spirometer — a device to measure and exercise lung capacity.

Sternal precautions — restrictions provided to a patient to help keep the breastbone or sternum stable while healing.

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