Everyone has a different journey with LDS, and everyone’s experience with their providers and institutions is also different. But there is value in learning from those who have gone before. Our goal was to compile some advice from those of our community who have undergone aortic root replacement or other vascular surgery to help others become educated and empowered as their LDS journeys may be leading them to surgery.

Thank you to members of the LDSF community for your time and thoughtfulness in creating this resource.
WHAT QUESTIONS DID YOU ASK THE SURGEON?

- What is the success rate?
- What is the mortality rate?
- What is the recuperation time?
- What are the risks of the surgery?
- How is the procedure done?
- How long will I be in the hospital recovering?
- How long will full recovery be after discharge?
- How long is the surgery (more for family waiting)?
- Once recovered, will my day-to-day activities change?
- What do I need to know about my medications before and after surgery?
- What are the risks of surgery vs. waiting?
- How many of these surgeries do you do each year?
- How long do you think I’ll be out of work?
- Will my pectus affect surgery?
- What kind of surgery am I getting done?
- Are there any changes I should make before surgery (diet, etc.)?
- Can I keep my own heart valve?
- Will scar tissue from a previous surgery impact this surgery?
- What is the likelihood for a re-do surgery?
WHAT DID YOU DO IN PREPARATION FOR SURGERY?

- I prepared myself mentally, physically, and spiritually. I continued to walk without putting myself at risk. I ate healthy and got plenty of rest so that my body was strong and prepared. I continued to pray. I see a psychologist and went to a couple of sessions. I made sure to surround myself with those I love and who love me. Support from my family and friends is so important. I had fun. I did not sit at home and crawl into a hole. There was crying, which is good to let it out, but I continued my life as normally as possible. I made sure to laugh.

- I talked to nurses and did as much research as I could on my problem and the surgery.

- I prayed.

- I worried.

- I did nothing.

- I hosted a “heart party” to spend time with people who love me so that I had some love to bring with me into the operating room.

- I made sure my affairs were in order, both at work and with regard to my personal obligations.

- I reflected and relaxed.

- I baked a bunch of food to keep in the freezer.

- I added my mom to my bank accounts so that she could pay my household bills for me if she needed to.

- I prepared power of attorney and power of health care papers.

- I cleaned the house, knowing that I’d be limited for a while.

- I had long visits with friends to tell them how much they meant to me.

For more information, visit LoeysDietz.org
WHAT DID YOU DO IN PREPARATION FOR SURGERY?

- I asked friends and family to provide meals during early recovery
- I bought comfortable clothing for recovery
- I made sure that my will/advanced directive and other paperwork and financials were up-to-date. I had a family member informed on all bills and other affairs that might come up while I was recovering in the hospital
- I made sure that my pets would be taken care of and that someone would be getting my mail
- I had my house ready and comfortable for my return (shower chair in place, wedge in bed)
- I let my friends and family know so that they could pray for me
- I did some walking and a lot of meditation
- I did research on the procedure
- I tried to lose some weight
- I got a pedicure, haircut, etc.
- I stayed as fit as I could and mentally tried to look after myself, too
- For my first operation, I was in a panic until I realized there was no other option and I had to take my chances. The second operation was more planned and I was calmer and knew what to expect
- I just tried to find out as much information as I could
- Two days before the surgery, I ate all my favorite junk food

For more information, visit LoeysDietz.org
WHAT DID YOU DO FOR PRE-OP EVALUATION?

- Surgery pre-op ranged from one day to one month prior to surgery
  - Echocardiogram
  - EKG
  - Blood work
  - Chest x-ray
  - Updated CT scan
  - Saw cardiologist
  - Met with anesthesiologist
  - Met with a counselor and surgeon’s PA to talk about post-op at-home needs

- I did not donate blood to myself. I ate no food for 12 hours before surgery. I showered with a gross smelling special soap the night before and the morning of surgery

For more information, visit LoeysDietz.org
HOW DID YOU MAKE A DECISION ABOUT WHAT TYPE OF AORTIC VALVE?

• Mechanical - an easy decision, as I didn't want more surgery, but they managed to spare my valve in the end

• My doctors made it for me. I wanted a tissue valve because I did not want to be on Coumadin. They did not agree because of my age. I have an ON-C valve, which does not require Coumadin and will last much longer than a tissue valve - hopefully, for the rest of my life. It is loud but you get use to it and it reminds me that I am alive and well!

• I was told if I had it early before there was much damage I had a 95% chance to keep my valve. If I had waited that percentage would have dropped

• My surgeon called me the night before surgery and asked which I wanted! We had talked before, but never landed on one. I decided mechanical because I did not want to get a cow/pig valve replaced every 10 years. Thankfully, they spared mine

• Valve sparing if possible, replacement if necessary

• My doctor made the decision

• N/A--valve sparing surgery

• Advice from doctors to try and spare it. They did!

• It was made for me - emergency dissection - I'm "young" so they went with plastic

• I wasn't really given an option between mechanical or bio valve. I was only 36 and did not want to have to have the bio valve replaced over and over and over again

For more information, visit LoeysDietz.org
WHAT DID YOU WISH YOU KNEW ABOUT SURGERY/RECOVERY UPON REFLECTION?

• How slow the recovery would be

• That the ICU is awful. I was sick from the anesthesia for a week. My main aim was to get out of there and onto a regular floor/ward

• Not to lay flat after open heart surgery! Worst pain I have ever felt! Recovery takes a long time. Be patient and give your body the proper time to heal

• How difficult it can be. Meals are very important. Make sure to eat enough protein and calories because it makes a huge difference

• The need to lie perfectly still for hours after surgery. How to get the breathing tube out. The lung drainage. I needed to know more about rehab

• Generally, I think patients need to be informed of "normal" things in recovery. For example: 1) that depression/anxiety is a normal part of recovery for major open-heart surgery. This caught me by surprise. But I understand that one can only be so prepared for this kind of thing. 2) heart complications, such as a-fib, are normal. I experienced a few days of intense a-fib and it caught me completely off-guard. I did not know what was happening or what to do

• I wish I had known about the extent of possible addiction to the pain pills

• I wish I had known about the scars that would be left by the drainage tubes

For more information, visit LoeysDietz.org
WHAT DID YOU WISH YOU KNEW ABOUT SURGERY/RECOVERY UPON REFLECTION?

CONTINUED

• I wish I had known about the chest tubes and how they would feel in my chest afterwards. They weren’t painful but I just couldn't figure out what was rolling around in my chest. Waking up while my breathing was still intubated was probably the worst part. Pain and mental comfort was really under control.

• I should have done more exercises regarding core strength and balance, and made sure my GI system working very well. My expectations about recovery time/experience were naive.

• I wish I had known about the severe pain and bruising, and just how hard recovery was going to be and how long it was going to take. I wish they would have warned me about the brain fog, forgetfulness, memory problems I was going to have. I wish they would have told me about the depression that could (did) happen, so that I wouldn’t be scared when I couldn't stop bursting into tears at the drop of a hat. I like to know up front as many potential scenarios as possible. It's scary when something happens and you aren't prepared for it and don't know why it's happening and if it's normal or not.

For more information, visit LoeysDietz.org
TELL US ABOUT YOUR INPATIENT STAY

- It was horrendous! ICU was dreadful as was the step down unit

- ICU was very stressful. I couldn’t keep anything down. It was too hot, too noisy, and too bright. I had a collapsed lung while intubated and could sense something was wrong. It was like having 'locked in' syndrome until you are brought around. There were no problems with the regular floor stay. I needed help daily getting up and about (showered, etc.), though. You really need a close relative to stay with you

- It was supposed to be the usual three to five days, however, it ended up being 14 days due to having both my valves replaced at the same time and starting on Coumadin, which was hard to get regulated on

- It was okay. It was hard on the first day because I couldn’t move much. However, it did get easier as the day passed by

- I am HUGE on self advocating. Nurses are amazing and I completely respect everything they do, but I know my body and I want to know what is going on. I have had several stays. The sooner you sit up, stand up and walk, the better. Of course, only if you are in the right condition. I make sure I am getting my meds, such as pain meds. You have to ask for them and it is important to stay on top of pain so that you can rest. The more rest you get, the better for healing. I always sleep most during the day. I may be a bit of a pain, but I do not give nurses a hard time about what I am supposed to do on my end for my recovery. I always have someone with me to help advocate

- Nurses are wonderful at the hospital and always encourage you to try to do some walking and eating. Control your pain by making sure you take your pain pills when needed

- I didn’t like not knowing when the physician would come and that there would be a crowd of students with him

- I slept most of the time
Tell Us About Your Inpatient Stay

Continued

- Overall, it was positive. 1) I was in cardiac ICU for about 30 hours and CCU for seven days (eight total). 2) My wife stayed with me for a few days. Our family watched our kids to free her up for that and I’m glad she did. 3) Nurses were patient and helpful. 4) Food was difficult, probably because I was often nauseated and not feeling well. 4) My surgeon and his physician's assistants were somewhat unpredictable in their regular visits and recovery update. 6) Sleep was very difficult, both because I was not well and due to the constant noise on a CCU

- The first few days are foggy. Both cardiac surgeries resulted in 10 day + stays. Some emotional therapy or support was needed by that time

- The most shocking thing is that the day of my surgery the nurse came in at night and made me stand up! I was shocked and completely not mentally/physically ready. The stay was pretty easy. I do remember my lungs were filling with fluid the first night and I couldn't breathe (which was quickly fixed but very scary), but that was the only complication. I was in the ICU for two days and left the hospital after eight days

- They got me out of ICU with 24-48 hours, then on my feet within 24 hours after that. Trying to pee after having the catheter was probably the most uncomfortable thing

- I did not sleep well at all; family member always stayed with me at night

- The first four days, I was in bed all the time and had the wound packed as it continually leaked. After that, it’s really just difficult being in the hospital

- I had excellent inpatient care at the hospital. I liked that they had everything in one area. You are put in a cardiac ICU room directly by the nurses station and then moved just down the hall to a regular room when you are out of ICU. Excellent care! I had issues that came up almost every day I was in the hospital and they were on top of it
WHAT RESOURCES (INTERNET LINKS, HOSPITAL INFORMATION OR PAMPHLETS) DID YOU FIND HELPFUL?

• With the first operation in 2000, there was nothing; I was terrified and just had to brave it out. By the second operation in 2012, there were online videos even! Internet gave full explanation of procedure
• I searched on the Internet
• I didn't use any links, hospital information, or pamphlets. I asked the doctors many questions that were answered which was either very scary or okay
• My surgeon had some pamphlets with pictures of the surgery that were helpful
• I did not do much pamphlet or link browsing. The greatest resources were: 1) my wife, who did much of the research for me, since my job is demanding and I had little time to prepare and 2) my visit with the surgeon. Few things beat an unrushed discussion with a knowledgeable surgeon with good people skills
• Best resource was asking others what to expect
• I feel like I was internet searching for a month leading up to the surgery. I spent hours trying to find images of scars to try to imagine what I would look like afterward. I spent a lot of time reading blogs written by people recovering from surgery. The hardest part was finding images of scars that were taken 1+ year after surgery, and finding information for people who are having planned surgery and young people (below 50)
• I thought the recovery therapy materials were helpful
• None of that really. I found that my most helpful resources were people I knew and trusted that had either gone through it (or a similar procedure), had medical training, or simply knew me
• I didn't really use any, as I was in a poor state mentally and didn't have much interest
• The hospital gave a great booklet on what to expect in the Cardiac ICU. It was helpful. I found a website for aortic valve replacement patients that was very supportive. I connected with a woman online who had been through the same procedure and she gave me lots of great advice
• I didn't get any
• All of it!
DID YOU USE CARDIAC OR OTHER REHAB? WAS IT HELPFUL?

• I didn't get offered it
• No
• Yes
• Whatever rehab is offered is always helpful. I use whatever is offered while in the hospital. I have never done rehab after being discharged
• Not enough; it was not convenient. I flew home so had to get rehab at a local hospital that knew nothing of my surgery or condition
• I had some rehab in my eight days of recovery, but nothing was prescribed after that. In the hospital, they made me do regular walks and the lung/inhaler volumetric thing. Yes, it was helpful. Afterwards, I attempted to keep up the daily walks, and progressively added light exercises.
• No, I walked and rehabbed myself
• I did cardiac rehab and it helped a lot
• I had PT in the hospital but nothing else after that. I asked for PT to help regain muscle strength across my chest because I was having a lot of pain, but I was denied
• Yes. The information given was helpful for the fastest recovery possible
• Yes. It was definitely helpful. Even though I didn't always enjoy it - I never skipped
• Yes, I used cardiac rehab for four weeks. It was extremely helpful but mostly because it was something to get me out of the house. During recovery, when my mom had to go back to work and I was at home alone, every day blended into each other and it was hard to snap out of the fog. With rehab, I could at least focus on what day it was, get out of the house and get active

For more information, visit LoeysDietz.org
WHAT WAS RECOVERY LIKE AT HOME?

• Great
• Overall good
• It was okay
• Long and slow
• First surgery was very long recovery but second wasn’t as bad
• Leaps and bounds. Need your rest though. Felt sick initially travelling anywhere, too
• Best to have someone that can be with you at all times. I am lucky to have my incredible mother. I either go live with them or my mother will come live with me. Usually, for about 2 weeks. I give myself this time to rest as much as I can while still doing all of my breathing and other exercises as instructed. It feels good to be in own bed, own clothes, take a shower and eat normal food! Good to have a routine. Keep a log of meds
• Very hard at times. I needed as much help as possible from everyone
• It was great to be home with family and friends. You have to be disciplined and do your exercises and breathing religiously
• I spent eight weeks in the Bay Area. Mutual friends, who were away from their homes there, let us use them for a few week
• As an adult, I stayed at my parents house for one to two weeks after. Don't be babied; you need to get up and get things for yourself. It's like rehabbing yourself. Don't let people wait on you constantly
• It was fine, but you have to remember that it is up to you to push yourself
Recovery at home was possible because I had a family member or friend with me to help out, and a nurse came to draw blood and check my scars so I wouldn’t have to go to the hospital so often. It was hard to lose some independence during that time - I needed help showering (and had to ask the landlord to remove the shower door so my shower chair could fit). My couch was too low so I couldn’t sit on it, so we had to buy a new chair for me to sit and sleep in. If I was going to be home by myself all day, I would need help out of bed and to be tucked into the reclining chair for the rest of my morning sleep.

I took it easy, but knew that getting up and walking and breathing were also beneficial in making sure my body was rehabilitated to normal functionality.

It was harder than I thought it would be although I had to go up and down stairs to get to a bathroom throughout the day.
HOW LONG UNTIL YOU FELT BACK TO NORMAL AFTER SURGERY? HOW ARE YOU NOW?

- My first surgery took six months but the second one only took about 4 months.

- Three months. I’m fine, but never ‘back to normal’ - too much has been done to my body. I live a normal life though.

- Six weeks, and I’m great now!

- I think it took a month or two to fully recover and now I no longer feel light headed or fatigued.

- I am on my third week after surgery and I am having bad days and good days. I will say, I still have at least another month or two before I expect to feel better.

- It was six months before I felt somewhat normal. It really took a year to get back in the swing. I am good now. No one would know. I’m a little slower and weaker, but lead a pretty normal life.

- My surgery was July 9, 2015. I think I felt mostly normal by January 2016. However, I will never be as strong as I was, say, about a year prior to surgery. Since I found out that I have a connective tissue disorder, I’ve toned everything down. Now, I am doing well. I was able to get back to snow skiing this winter at high altitude, which was a good indicator of recovery. I have LDS-related insomnia, so am tired regularly.

- I don’t remember exactly, but the sternum healing takes time. I feel good except that I feel like I never fully regained my strength after my 2014 surgery, due to continuous complications with atrial fibrillation.

- You never come back 100%. The older you are, the longer it takes and the more you lose.
HOW LONG UNTIL YOU FELT BACK TO NORMAL AFTER SURGERY? HOW ARE YOU NOW? CONTINUED

• It depends on the surgery. I’ll pick my last open heart. I think it took me a good six months to feel strong again, but I have to be honest, I have never felt the same. You adjust and life goes on. I live by what God brings me to, He will get me through. These days, I am great. I have my off days for sure. I listen to my body and if I am tired, I take it easy. I am back to exercising, part time work, volunteering, spending time with family and friends, and I am in a loving relationship. Life is good. You have to have faith!

• I would say it took about four months to feel like a completely normal person again, but I started feeling more like myself at four weeks, when I was able to get off daily Tylenol and was able to poop like a normal person again! Now, two-and-a-half years later, I feel great! Totally recovered. The only problems I have now are a weird bump on my sternum that can be irritated by bag straps or bras and occasionally, I feel like my muscle gets stuck on a wire or something - there will be a sharp pain, but it goes away quickly. Also, I have numbness in my right shoulder blade that was never there before. At the 2016 conference, Dr. Dietz said it might be nerve damage from how the anesthesiologist positioned my head during surgery

• One week - out of hospital. One month - walking without being physically drained. Two months - back to feeling physically normal again. Mentally and psychologically, the recovery was about one year. A mental therapist/coach would’ve have been a good recommendation in dealing with depression and mortality issues at hand after surgery

• I’m still waiting! Life will never be 'normal' again and I've accepted that

• It took me a full year to feel "normal" although my normal now is not the normal I felt prior to surgery

For more information, visit LoeysDietz.org
WHAT DID YOU FIND MOST HELPFUL DURING RECOVERY?

• Having support from family and friends
• Resting and having family help
• Walking; the sooner you are up walking, the faster you feel better
• Being positive and having the will to live on
• Having someone to help me at home
• Resting; lots of rest and good food
• Having my two pups by my side. Walking them. Listening to music. Home care (could have used more)
• In the hospital: 1) When either the surgeon, PA's, or others came in and had unrushed discussion with me about my recovery. 2) Having my spouse there. 3) Being forced to get out of bed and either walk or sit in the chair. Out of the hospital: 1) Having unrushed time off work (about eight weeks) to recover. 2) Taking some relaxed vacation time during my recovery with my family to the ocean. That was very helpful. 3) Having unrushed discussions with my surgeon about my recovery
• Sitting upright to sleep for a few days or a week. When first beginning to sleep on side, use pillows and keep shoulders open, do not fold in. Use pillows!
• Sleeping
• Having someone around to help me and keep me company during the day for the first three weeks was a MUST. I was really lucky to have my family able to take time off work to come up north to take care of me
• The pain management. It was stellar
• Walking and rehab; eating protein; sleeping; having my husband's never ending love, help, and support
• Having family and friends around to look after and encourage me
• My support of friends and family. It is so important to have people by your side when going through something this traumatic

For more information, visit LoeysDietz.org
HAVE YOU HAD MULTIPLE AORTIC OR OTHER ARTERIAL SURGERIES? HOW DID THEY DIFFER IN YOUR EXPERIENCE IN THE HOSPITAL AND RECOVERY?

- First one was in 2000, for type b dissection. I was in huge pain after op as such a large wound from back to front. The second op was more planned to replace aortic root - less painful. Both times, I felt so sick for five days and couldn't keep anything down. This really affected my recovery and made me distraught in ICU. Also, I had to have blood drained from around my lungs after the second operation, which was a very painful procedure. I found it a lot easier to sleep after the second operation and felt more peaceful. I had my own room and was in less pain overall.

- Yes, I had a previous mitral valve replaced in 1998, a carotid artery bypass, vertebral "glued" and 3 subclavian stents. My first open heart, I was 17 and didn't know what to expect so that was hard and awful. The carotid was very painful because it felt like my head was 1,000 lbs and I had to sit up for several hours after my procedure. The subclavian stents were a walk in the park. The vertebral "gluing" was another horrible procedure due to the fact I was kept awake and they kept me talking and i was in excruciating pain.

- I have had multiple surgeries. My first open heart was to repair my ascending aorta. I had a fast inpatient and at home recovery. It all depends I believe. My second surgery was to repair and replace my descending aorta. I was in ICU for six weeks, mostly sedated the entire time and then in rehab for two weeks before I went home. My recovery took much longer. Honestly, it can take a full year or even more to completely recover. And then your body is different. That is something definitely to be expected. My brain surgeries were actually the least painful and quickest recoveries. My second open heart was a quick stay (two weeks) and recovery time at home was faster. I feel because I was so mentally and physically prepared for that surgery.

For more information, visit LoeysDietz.org
HAVE YOU HAD A PLANNED VS. EMERGENCY SURGERY FOR DISSECTION? HOW DID THESE RECOVERIES DIFFER?

• Yes, I have had both! Emergency was so tough on my husband and children, so frightening, but at least it was just done. Planned is difficult on the mind!

• Not much difference, just in a better place mentally for prepared surgery

• No, not yet and let's hope not!

• I had a emergency surgery for dissection, but I recovered quite fast for someone with a major surgery. Just sit up or move around as much as you can to recover quickly

• I have had both. My first was emergency for my dissection. I was in very good shape so my body handled the surgery well and I recovered nicely. My planned surgery recovery took much longer, but I did have complications and was in the hospital for much longer. I think planned makes for a better recovery but like I said before, it all depends on what happens during surgery

• Yes. The first time was emergency and I was much younger

• Emergency was very slow recovery but planned was quicker

• Two planned and two emergency. Emergency recovery was harder - seemed like the surgeon was "rouger"

For more information, visit LoeysDietz.org
I REALLY WISH SOMEONE HAD TOLD ME...

• They’d had it done and were fine!

• How sore you are afterwards and to hold a pillow when laughing, coughing or talking. Take your time, it's not a race. You will get there following doctors orders! Plus, stay up on pain medication - DO NOT WAIT UNTIL YOU FEEL PAIN TO TAKE SOMETHING - it takes that much longer to get rid of it!

• Watch your diet. You need your calories and your food

• What to do right after surgery. I could not communicate with the nurses because I had tubes down my throat

• To quit working after the first time. Might not have been a second or third time

• About those draining tubes and the scars left by them. My open heart scar healed beautifully, my leg scar is pretty good, but those tubes left big dark scars and I was really upset about them when I saw them

• To talk to a mental therapist after surgery. There’s a lot that has changed with your body capabilities which translate directly to your mental state

• The emotional recovery (especially after emergency surgery) is just as long as the physical recovery

• Things could be OK. There is so much negativity about it, with very few glimmers of hope!!

• I wish they had told me about the depression and the brain fog that I suffered with for a year. I was scared that I wasn’t going to be able to work anymore because I had such a hard time with retaining memories. I still do (five plus years later) but not as bad and I have learned ways to deal with it
WHAT ELSE?

• The hospital you pick is as important as the doctor you choose

• Menstrual cycles: the stress from the surgery threw off my cycle so it was 46 days long, I ended up starting my period the morning of my surgery and had a lot of stress because of it and during my stay in the hospital. No one ever talks about that

• Always bring anything that entertains you if you're staying overnight at the hospital

• Prayer was a comfort before and after. I would have liked more support from a priest or chaplain

• The support of people - family, friends, professionals, or strangers with the same problem: whoever is most helpful to you and your situation is VITAL
WHAT ADVICE DO YOU HAVE FOR SOMEONE NEEDING SURGERY?

• No choice really - have to do it. Be informed. Contact others who have had it, but don't listen to horror stories. Some people are affected far worse than others and their condition does not reflect yours

• Make sure you are comfortable with the doctors and surgeons you choose. Be your own best advocate, fight for what you want, have a plan and make sure they follow the plan unless, of course, something comes up unexpectedly so that they can't follow it! Walk, walk, walk I can't stress that enough as it helps so much. YES, you don't feel great but walking gets the blood flowing again and I feel speeds up the healing process

• It may be a risky and long surgery, but you know it is best for your body.

• Stay positive. Obtain all information possible. Talk to your team of doctors and make sure all are on same page. Pray

• Do it!! Life is beautiful and worth it!!

• Be patient. It will take time. Depending on your age, your body reconditions pretty quickly. For every day laid up, it takes about three days of rehab

• Research and speak with others who have had the same surgery

• Find a surgeon who doesn't talk down to you - someone who understands that you are ultimately the best at understanding your health, so that they know that they need to answer your questions and let you know the details

• Have it done sooner rather than later. Recovery is easier the younger you are

• Ask all the questions!

• Just know yourself and your body - people will try to make you eat, walk, breath, and many other things you don't want to do. Most have your best interest and recovery in mind. Work hard at recovery; don't be a wuss!

• Don't take it lightly. It's a major surgery. But at the same time, know you're in good hands and everything will be okay
• Take your time and find out all you can from your team

• Get an experienced surgeon in a center of excellence, know exactly what you’re having done, have a relative with you who is also fully informed of the condition and your meds

• Be your best advocate, ask questions until you are comfortable; nothing is too stupid to ask! If you don’t connect with that doctor, go with someone else. Make sure they (the doctors) know your plan just like you do

• You have the best doctors and surgeons that are looking after you. Don’t worry too much. Be positive

• Offer it all up to God. (Forgot to mention above that I always pray for the doctors and nurses) Prepare as much as you can so that all you have to worry about is your recovery. Ask all the questions you can think of so you are as comfortable as possible going into surgery. Have a support system

• Try to get in shape before going in. Get up and around as soon as you can. Have it done at a great place by an experienced surgeon

• 1) Schedule plenty of time off work if possible (eight weeks or so). 2) Have a discussion with your employer about the serious nature of the surgery. 3) Do your best to recruit either a family member or close friend to be with you, especially for the first few days out of surgery. 4) Prepare your spouse, family member, or friend who will be helping take care of you. It’s taxing on them, too. 5) Be prepared for depression and anxiety post-surgery. Though it’s normal, it is still difficult. If possible, try to have some good reading and a friend or family member around just to get your mind off things. When you are able, schedule some moderate, enjoyable activities (again, I went to the ocean for a time). 6) People may consider recruiting friends and family to participate in a Caring Bridge Fundraiser. It is a website where you can do your own fundraising. A friend of our family started one for us and it was amazing. I think something like $8,000 was raised for us, which helped cover travel costs, time off, etc.
WHAT ADVICE DO YOU HAVE FOR SOMEONE NEEDING SURGERY? CONTINUED

• Buy comfortable clothing for recovery at home. Use word finds or computer games to stimulate the brain; TV does not help cognitively

• The younger you are, the easier it is

• Have a helper, someone to cook and help you in an out of bed, someone to drive you and do the dishes, and vacuum the house, and make you decaf coffee

• It’s nerve racking but the drugs they give you before the anesthesia helps take that edge off

• Get your body ready - physically; learn to tune-out the people (or things) that aren't helpful post-op - you need everybody and everything on your side (minus some occasional tough love or butt kicking!)

• Don’t be afraid to ask directly to your surgeon any questions, even if you feel like a nuisance

• It’s okay to be scared. It’s normal to have depression after this type of major surgery. If you feel like crying, go ahead. It’s normal for your memory to be out of sorts and it will come back. For your hospital stay: bring a robe, a few pairs of pajama pants, good walking shoes (they make you walk the halls A LOT), a button up shirt to go home in, (for women) comfortable sports bras that close in the front, dry shampoo, chapstick, and throat lozenges (it’s dry in the hospital)

• It’s scary but it is possible to get through it. Have faith and educate yourself on everything you can related to this surgery and LDS

For more information, visit LoeysDietz.org
HAVE YOU HAD MULTIPLE AORTIC OR OTHER ARTERIAL SURGERIES? HOW DID THEY DIFFER IN YOUR EXPERIENCE IN THE HOSPITAL AND RECOVERY? CONTINUED

• I had an abdominal aortic aneurysm repair done six months before the valve surgery. It was much more painful. Recovery was more just healing than rehabbing

• Aortic 2005, mitral in 2014. For some reason, I was more alert after the mitral valve surgery. Did not like the effects of the shots to pull the water out of me. Made me feel horrible

• Different hospitals mean different experiences

• Meeting the expectations of docs, nurses, rehab et al was 'easier' because I knew what was expected of me and when I could say 'no'