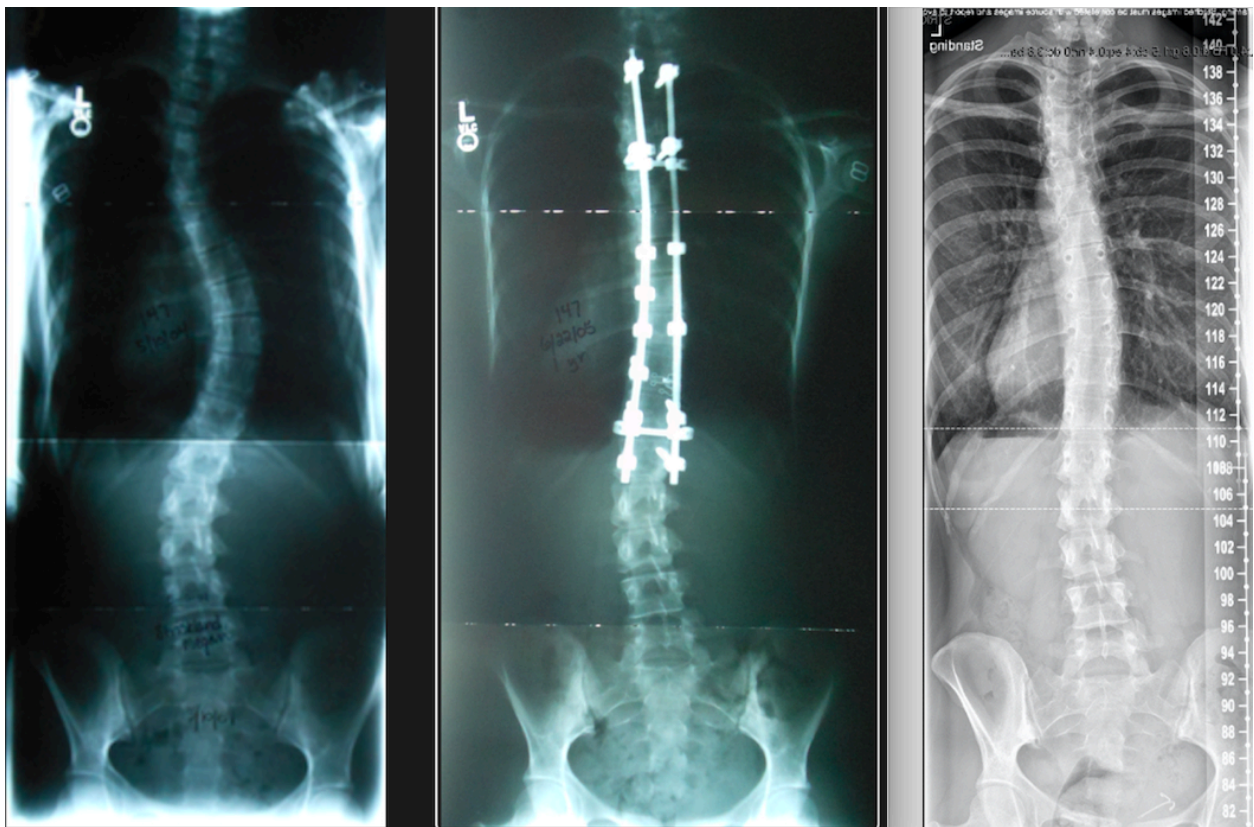


10 Tips for Preparing Yourself and Your Support Network for Major Surgery

(especially for those who don't have as much support as they need)



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Introduction

When I was 14, I had an invasive spinal fusion surgery to treat scoliosis. The surgeon messed up. He left a screw poking into the tendons of my left shoulder. For the next 12 years, the adults in my life valued the reputation of the surgeon over my own lived experience. They told me my pain wasn't real. I was an over sensitive girl, and my pain was somehow my own fault. I coped by dissociating from my body and trying to forget my recurring nightmares about having another surgery.

When I was 26, I had finally traveled far enough away from that surgeon's sphere of influence that I was able to find a doctor who valued my experience over the surgeon's reputation. My new surgeon informed me that my choices were to have corrective surgery or to continue enduring the pain that had begun to make me fantasize about dying. Though it meant literally facing my worst nightmares, I chose to have the corrective surgery.

For the three months that passed between my consult and the corrective surgery, preparations for the long recovery path that I knew was ahead of me became a persistent buzz--sometimes loud enough to be all-consuming and sometimes a hum behind the rest of my life. Now, I type this with a fresh scar and surgical pain streaking down my spine and through my muscles, slowly healing into what will hopefully become a healthy future that I hadn't thought possible.

When I think back to my pre-surgery self--squeezing both surgery prep and long hours at my job into each day, while simultaneously managing the anxiety of oncoming major surgery--I feel sad for them, and I also feel proud of them. I had support from my friends and brother for which I feel I will never be able to say enough thank yous, but I didn't have anywhere close to the level of support I needed.

The medical industrial complex, like many other institutions, tends to operate according to the heteronormative assumption that adults are coupled and have a family unit supporting them. The medical staff I spoke with during my surgery prep assumed I had a built-in caregiver, either my parents or a (hetero) spouse. Yet so many of us don't have that kind of support.

For the first time since the Bureau of Labor Statistics began keeping track in 1976, there are now more single people living in the U.S. than there are people who are married. Single folks can build lives full of supportive community and chosen family, but surgery doesn't always come with the best timing. For me, I had been living in my city for less than one year when I heard the news from my surgeon, and building such a community takes time. How are single adults facing major surgery supposed to get by within a medical system that assumes we'll have a caregiver?

People who are in romantic relationships can also struggle to find enough support while recovering from surgery. Their partners might be unable or unwilling to take on additional caregiving responsibilities due to work, their own mobility limitations, feeling already full with

caregiving responsibilities, and many other reasons. For all adults facing major surgery without adequate support, I hope this list of things I did to maintain my survival might help.

I do not consider this to be a comprehensive resource guide for everyone. I speak from my own perspective as a single, late 20-something, white, queer, insured, assumed cis woman and survivor with U.S. citizenship, without caregiving responsibilities, and living in a shared home in a metropolitan U.S. city. I was fortunate enough to be able to cover my medical bills using savings. I was full-time employed at the time of my surgery and had enough accumulated overtime and support from managers that I was able to use 4 weeks of Paid Time Off days during my recovery.

I know that my race, class, citizenship, and cis passing privilege dramatically impacted the ease of my situation, as did not having kids or other caregiving responsibilities. However, I would like to share my personal experience because I hope it might be able to help other adults preparing for major surgery who, like me, need more support than they've got but have to move forward anyway.

These 10 tips focus exclusively on the period of time leading up to surgery. Later, I hope to create a separate set of tips focused on the recovery period.

1. Simplify your life.

Finding out that you need to have major surgery is like adding a full time job on top of the responsibilities and job(s) you already have. Something is going to have to go. For me, the things I cut were cooking--which hurts my back anyway--as well as my gratifying but often emotionally challenging volunteer gig. As I was preparing for surgery, I primarily ate inexpensive pre-made or boxed meals to save my energy, money, and time, and I took a hiatus from volunteering. For you, it might make sense to cut something completely different. Maybe cooking is a really important part of your selfcare routine and you choose something else instead. Whatever it is, formally decide to cut it until you've recovered from surgery.

In addition to cutting things out, allow yourself to take breaks from surgery prep. For me, the labor of surgery preparation involved myriad time-consuming tasks, including scheduling and attending doctors consults; obtaining X-rays, CT scans, and MRIs; tracking, contesting, and paying medical bills; and readying my body, house, and support network for my recovery period. During the three months I had to prepare, I allowed myself to stop at just one or two surgery prep tasks in a day if I could feel my exhaustion or anxiety rising, and to take breaks from surgery prep, especially after bursts of difficult tasks such as doctors consults.

2. Vigilantly practice selfcare.

Next, commit not to drop things that make you feel happy, calm, and taken care of. For me, it was regularly swimming laps, practicing yoga, hiking in nature, and spending time with friends. I unrelentingly committed to doing these activities as often as possible, even when work demands and surgery prep took up nearly all my time. During the last couple of weeks before my surgery, I was so committed to self care that I created weekly checklists to hold myself accountable.

04/24/16	finances	room	swimming	yoga	meditation	nature	friends	cleaning	therapy	surgery
Sun.	X					X				
Mon.			X				X	X		
Tues.				X					X	X
Wed.							X			X
Thurs.							X	X	X	
Fri.		X					X			
Sat.	X						X	X		

04/11/16	swim	yoga	meditation	nature	friends	cleaning	therapy	surgery
Sun.				X				
Mon.		X						
Tues.					X			X
Wed.					X			X
Thurs.	X							
Fri.					X			
Sat.			X			X		

Additionally, I encourage you to make an appointment with a psychiatrist or therapist. Major surgery can be isolating and anxiety-inducing for everyone, and it can be particularly challenging for people who have previously experienced trauma or surgery and/or who are part of a stigmatized or systemically oppressed group.

Orthopedic surgery is an extremely male-dominated field, which can be challenging for women and femmes, particularly those who have experienced sexual trauma. Hospitals can be unfriendly and unsafe for people of color and people who are not citizens of the U.S.. Hospital stays and medical crises can make you feel like you've lost your bodily autonomy, which can be challenging for people who struggle with control and body image. Having to take pain medications following surgery can create challenges for people who have experienced addiction. If you've had [previous major surgeries](#) or hospital stays, you may have [undiagnosed PTSD symptoms](#) associated with those experiences, which can be triggered by another surgery. Medical professionals might misgender trans and nonbinary people by using incorrect pronouns or unnecessarily gendered words for body parts, and they might assume heteronormative practices for queer patients. Generally, medical professionals do not take the pain of women and people of color as seriously. For these and many other reasons, it is important to seek trauma-informed and identity-affirming mental health care services when facing major surgery, particularly if you have previously experienced trauma or surgery or are a part of a stigmatized or systemically oppressed group.

I was weary of going to doctors appointments and accumulating medical bills, but I got myself a psychiatrist before my surgery anyway. I'm glad I did because I received advice and medication that significantly helped me during my preparation and recovery. I received treatment for my

pre-surgery anxiety and was better able to understand how my surgery and its associated medications might trigger my PTSD symptoms and develop a game plan for if it did.

I urge you not to make the same mistake I did--don't wait until only a couple of weeks before surgery. I really wish I had seen the psychiatrist earlier in my process of surgery prep and supplemented his care with seeing a therapist. I realize now that it would have been worth it even though I was already feeling burdened by the time and money of my myriad doctors visits.

I found a psychiatrist willing to work on a sliding scale rate that fit my tight budget, and he allowed me to pay once my surgery was over. If you're worried about the cost of mental health care, I encourage you to seek out organizations that offer free counseling services. If you have insurance, check to see what's covered, and use it.

3. Identify people who can provide emotional support.

From the moment my surgeon first suggested that I should have surgery up until the day of my surgery, I found it difficult not to bubble over with emotional surgery stories each time a colleague or acquaintance casually asked, "How are you?". Knowing that surgery thoughts would be omnipresent for me for a long while, I proactively warned the people I'm close to. I told them that I care about them and want to support them but that I was entering a phase of my life in which I might be more focused on myself than usual. I selected a couple of close friends and asked for their consent to lean on them for the next several months and ensured they were open to providing that type of support. However, I wish I had done a better job of communicating to those close friends what my expectations were. I am guilty of hoping for types of emotional support without explicitly communicating it, which is unfair to the person I'm expecting something from. For example, while I was staying in the hospital, I hoped for regular, "How are you feeling today?" texts when my close friends weren't able to visit, though I didn't adequately communicate that expectation.

While preparing for major surgery, everything in your life can feel high stakes, and likely it will be difficult for the people around you to understand this. I planned in advance to go on a hike with a close friend the weekend before my surgery because I knew it would help me feel more calm. A couple of days before our planned hike, my friend casually mentioned they might back out if the weather wasn't great. The threat of them backing out devastated me. Once I had calmed down, I attempted to explain to my friend that, though the likelihood that my surgery would result in paralyzation or death was slim, I was thinking about our plan as if it might be the last time I was able to hike. Once they understood how important the hike was to me, they assured me they'd do their best to go. This conversation revealed to me the disconnect between the mindset I was

in and the mindset my friends were in, and just how important it was for me to communicate my needs and my emotional state as a result.

4. Plan far in advance with colleagues.

At first, I hesitated to tell my colleagues about my approaching surgery. I thought it might be too risky to tell them before I firmed up details such as the date and anticipated recovery timeline. I'm glad I decided to let my colleagues know far in advance, however, because it made it much easier to incorporate my surgery preparations and recovery into my life at work. By involving my colleagues early on, I was able to create work project timelines around my surgery schedule. Also, I was freed from having to furtively intercept calls from my doctor while in the office, sneakily attend pre-surgery appointments during the workday, or make excuses for why I might seem distant or stressed. You will have to feel out the particularities of your workplace circumstance, but disclosing early worked well for me.

5. Get creative about finding people who can serve as caregivers.

If you are facing major invasive surgery, there will most likely be a period of time after surgery when you won't be able to care for yourself. You will need to find someone, or a rotating list of someones, who you can trust to protect you and act in your best interest. Get creative with finding these people. When you don't have a built-in person who's got your back like a spouse or a romantic partner, you have to break some of our societal molds in the pursuit of a caregiver. Brainstorm who in your social circles could benefit from and enjoy taking care of you.

When I needed a primary caregiver, my brother--who at the time was living in another state--wanted to move to the city I live in and find a job here. So, he took a leave of absence from his job and moved into an extra room in my shared house. As he cared for me, he used the time to apply for jobs. He was thrilled to have a reason to move to the city he wanted to be in and to be there for his sibling, and I was relieved to have someone looking out for me. Do you know someone who is trying to figure out if they want to become a nurse? Do you have a friend with a younger sibling or an adult child who needs a summer internship? Reach out to them! Think creatively about what your situation has to offer someone else.

Once you've found your person(s), be prepared to dedicate time and resources to equipping them to help you. Let them know ahead of time what you'll need their help with and what they can expect in terms of your abilities and condition once you're released from the hospital, and gather the required resources. Particularly if they are going to need to live with you for a period of time, take care to ensure they will be comfortable and well taken care of themselves. For

example, I made sure my brother would have his own room where he could find respite when needed, a comfortable bed, access to a gym, parking on my street, and access to public transit. Caregiving is devalued in our society, so it takes a lot of work and intentionality to ensure your caregiver(s) feels valued, appreciated, and taken care of.

6. Find someone who can be your advocate.

This is especially important for women, people of color, trans and nonbinary people, fat people, disabled people, people who are poor, queer, or HIV positive, people who have a stigmatized mental health diagnosis, and other people [whose pain doctors tend not to take seriously](#). During challenging pre-surgery appointments, an advocate could help you make doctors take your pain seriously and listen to your concerns, as well as help you keep track of the details of your surgery plan, weigh your options, and make sure you ask all the questions that need to be addressed.

Once you're in the hospital recovering from surgery, you likely will be too drugged to advocate for yourself all the time, but you will need someone to keep track of your medication schedule and to speak on your behalf to the nursing staff and surgical team should any problems arise. If you don't personally know someone who can serve as a health advocate for you, try investigating health advocate services. Some nonprofits, hospitals, professional associations, and insurance companies offer health advocate or appointment escort services.

I didn't have someone who could advocate for me, and I suffered as a result. For example, I knew that I needed to limit my narcotics intake during recovery because my body reacts negatively to them. I warned the surgical team prior to surgery, but I didn't have someone who could firmly reiterate my needs to the nursing staff once I groggily awoke from surgery. Despite my pre-surgery warnings and my hospital-provided red narcotics allergy wristband, the nurses pumped me full of narcotics. I wound up with a massively distended belly, abdominal pain that was worse than my surgical pain, having to endure a litany of uncomfortable and costly interventions over the course of two extra days in the hospital, and persistent gastrointestinal problems. An advocate could have prevented me from suffering through all of this by firmly communicating my needs to the nursing staff on my behalf when I was too drugged and in too much pain to do so myself.

An advocate also could have eased my pre-surgery consults. I tended to be upset, easily triggered, and anxious during these appointments and not in the best state of mind to keep track of the details of my surgery options or to stand up for myself with disrespectful doctors. For example, an advocate could have helped me remain calm and ask the right questions when the surgeon whom I consulted for a second opinion dismissed my 12 years of chronic pain as if I had imagined them, acted as if it were absurd for me to wish to be pain free, and disparagingly

said I wasn't "in the right state of mind" for surgery. Please learn from my mistake and prioritize getting yourself an advocate.

7. Communicate clearly how people can help you.

When friends, family, and colleagues asked me, "How can I help?", I often found it so difficult to respond that it was easier to say, "I'm fine, but thank you for offering!". I needed so much help, however, that I couldn't continue refusing. I created a Google Doc ([example linked here](#)) to communicate to my friends, family, and colleagues how they could help. Whenever someone offered help, I shared the link to the document with them. At first it felt strange and wrong to ask for help so directly, but the Google Document helped my friends feel useful, involved, and well-informed, which they appreciated. Since none of my friends knew what to expect from major spinal surgery, they were relieved to be told exactly how they could help. Also, it helped me ensure that I received the support I needed. It takes a lot of work, emotional labor, and vulnerability to help people help you, and consolidating the information into one place can help you conserve your energy, ask for help even when you're feeling tempted to demur, and reduce the number of times you have to repeat yourself.

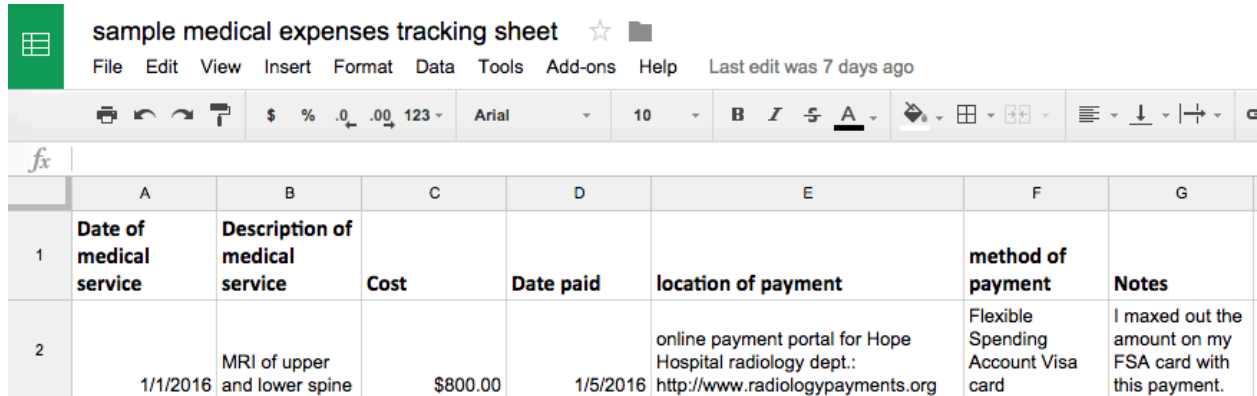
I split my Google Doc into three sections:

- Logistical information such as how to get in touch with me during the different phases of recovery as well as basic information about my surgery and medical condition
- Ways that people far from me could support me, including a wishlist of items that people could send me in the mail
- Ways that people nearby me could support me prior to surgery, while I was in the hospital, and after surgery

Another source of inspiration for how to communicate your needs could be [this guide to creating an inFrequently Asked Questions \(iFAQ\) page](#) for yourself. Regardless of the format or platform that you think would be most accessible and appropriate for the people within your network, establishing some kind of list of the ways that people can help you can ease your burden to communicate emotionally difficult information and can help your friends best help you.

If you live in a shared home, you might need to make specific requests of your housemates. In advance of my surgery, I explained to my housemates that I would have mobility limitations for several months after my surgery, and we discussed how we could continue ensuring that the house remains clean and the chores done without overburdening any of my housemates.

8. Develop a system for tracking medical bills.



	A	B	C	D	E	F	G
1	Date of medical service	Description of medical service	Cost	Date paid	location of payment	method of payment	Notes
2	1/1/2016	MRI of upper and lower spine	\$800.00	1/5/2016	online payment portal for Hope Hospital radiology dept.: http://www.radiologypayments.org	Flexible Spending Account Visa card	I maxed out the amount on my FSA card with this payment.

I used the following methods to track my medical bills. These exact methods might not be right for you, but it is important to establish a system that does and to consistently follow it:

- Maintain a list of the different online patient portals and bill payment systems you use. In my experience, different types of bills--e.g. radiology fees vs. physician's fees vs. hospital fees--tend to use different online payment portals, each requiring a separate username and password. I included the following information on my list:
 - The type of medical service that is associated with the patient portal or online billing system
 - The web address of the patient portal or online billing system
 - My corresponding username and password
- Create a spreadsheet of your expenses and proactively fill it out. [Here's a link to a sample spreadsheet](#) that includes all the fields I used in mine. As soon as you schedule an appointment, record the appointment in your spreadsheet so that you aren't surprised when the bill arrives, which could be months later once you've long forgotten about the appointment.
- Develop a filing system to organize the bills that come in the mail. I had three different file folders:
 - One that held FYI type documents related to my insurance plan,
 - One that held receipts and bills that I had already paid (if I paid online, I'd write the date and method of payment on the bill before filing it), and
 - One that held how-to guides and other information I was given specifically about surgery.

I also designated a basket on my bedside table for bills that came in the mail that I had not yet paid. I kept them in plain view so that I'd remember to pay them promptly. Once I paid, I'd have the satisfaction of moving them into the paid file and out of sight.

- On your computer, clearly label folders and file names to organize electronic bills, surgery information, and related files such as the above mentioned list of patient portals and spreadsheet of bills.
- Keep in mind that many types of medical care have hidden fees and are billed in separate parts. For example, as a method of managing my chronic pain prior to surgery, I received injections in my back. The bill for the injections came in two parts: 1.) the physician's fee to pay the doctor who administered the injections, and 2.) the hospital fee to pay for the medical equipment used during the injections. For an MRI, the bill also came in 2 parts: 1.) the cost of the MRI itself, and 2.) the fee for a radiologist to read and interpret the images (even though what mattered most to me was my surgeon's interpretation of the images during my consult with him). For my surgery, the bill was split into innumerable parts for each type of doctor on the surgical team from the anesthesiologist to the surgeon, the long list of medications that were administered to me orally and through IV, the equipment I used such as a walker and a spirometer, and much more.
- I learned while contesting a charge on my hospital bill that patients are charged each time a doctor pokes their head into their hospital room, even if the patient is asleep and the doctor does literally nothing but glance at the patient from the doorway for a brief moment. I was charged for several hundred dollars in physical therapy fees even though the extent of the interaction was two doctors waking me up from much needed sleep, asking me if I needed physical therapy, and then leaving when I told them what I really needed at that moment was rest. I encourage you to request an audit of your hospital visit bill once you receive it. My hospital provided a free service in which a nurse went through my bill line by line to double check it was correct. I wasn't able to have the fraudulent physical therapy fees removed, but the auditor did find that I had been charged for various medical equipment that was not actually used on me, and those associated costs were removed from my bill.

9. Stock your house with everything you will need.

The particularities of your surgery might require different sorts of supplies during recovery than mine, but here are three general categories of items that were helpful for me to stock up in advance of surgery:

- Personal grooming products that can help you keep clean in the absence of a shower such as facial toner, moist towelettes, dry shampoo, and talc-free body powder. I highly recommend getting a sprayer attachment for your toilet that converts it into a bidet.
- Any OTC pharmaceuticals you think you might need, such as stool softeners (narcotics are severely constipating), probiotics to counteract the side effects of antibiotics, anti nausea medication, Tylenol, and naproxen sodium (Aleve).
- As much ready-to-eat food as you can afford and have the room in your house to store, such as boxed and canned soups, frozen foods, precooked rice, nutrition shakes such as Boost and Ensure, instant ramen, oatmeal, granola bars, pudding, yogurt, and snack foods. Going into surgery, you should have enough food in your house that you will not need to go grocery shopping until several weeks after you get out of the hospital.
- Backups of any product you use on a regular basis that might run out while you're in recovery, including toilet paper, shampoo, toothpaste, deodorant, pet care products if you have a pet, and cleaning supplies. It will likely be very difficult for you to run errands for a significant period of time after your surgery, so try to set yourself up so that you won't need to do any shopping while you're recovering.

You can find a more detailed list of some of the items I stocked up on by checking out my [Google Doc wish list](#) that I shared with friends.

Also, I prepared my house for surgery by nesting. Since I knew I wouldn't see much of the world apart from the inside of my house during the first several weeks after I was released from the hospital, I tried to make my house as enticing a place to be trapped as possible. I cleaned, organized clutter into storage bins, adopted more effective housekeeping systems with my housemates, bought some indoor plants, planted a backyard garden with my housemates, displayed artwork, and generally tried to fill my house with beauty and calm.

10. Throw a party.

Because I had already had spinal surgery once before, I knew exactly how difficult it is. I anticipated that the night before surgery would be emotionally challenging and that I would crave distraction from my nerves. So, I invited a bunch of friends to my house the night before.



That night, I was so busy topping off peoples' glasses, setting out snacks, and enjoying the pleasure of seeing friends from different parts of my life spark new connections that I wasn't stewing in invasive thoughts about worst case scenarios. When I sent out invite messages for the party, I included a link to my "here's how you can help me" Google document, so some of my guests brought along food items and other gifts to help me stock my pantry in advance of surgery.

Once it was time for me to take my doctor-instructed antibacterial shower and attempt the doctor-advised good night of sleep, I asked my guests to help me clear away the party accoutrements and ready my house for my recovery period. My friends were happy to pitch in, and the house became cleaner than it had been before the party. Following the party, I asked a friend to spend the night with me and another friend offered to drive me to the hospital in the morning. Surrounding myself with friends made the last few hours leading up to surgery bearable and kept me from drowning in scary thoughts.

Bonus tip:

I learned the hard way (i.e. the expensive way) that mobility limitations can result in frequent phone dropping. I wound up buying a new phone during a time when nearly all of my paycheck was going toward medical bills. If you're anticipating similar mobility limitations, learn from my mistake and invest in a sturdy phone case before you go into surgery.

Congratulations on making it this far! The items on this list require a lot of work, but you're a champion, and I know you will be able to prepare yourself and your support network for your surgery. Even though you might feel alone, you are not alone in this. While I was immersed in surgery prep, I felt isolated from even my closest friends because no one I knew had similar experiences. I felt most seen and understood when a new colleague, having heard of my upcoming surgery, told me that she had had back surgery a couple of years prior. She said, "I was reading your document and honestly, I forgot how much work it is. I really empathize. I'm married, so I had my husband around to take me to the bathroom and help me get dressed and everything. That is all to say, that it does take a village, and you've clearly identified that." I cried it felt so good to hear my experiences validated. The physical and emotional labor I put into preparing myself and those around me for my surgery was largely invisible, though it exhausted nearly all my time, energy, money, and thoughts, and it felt so good for someone to acknowledge the work I had done. I acknowledge and congratulate you for all the work you're doing to prepare yourself and your network for your surgery, and I hope you take care to acknowledge and congratulate yourself as well. You deserve it.