

SPINAL FUSION SURGERY

Helpful tips for
Patients and Caregivers



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Supporting Discoveries in Spinal Deformities

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About US



We are four girls, ranging in age from middle school to high school, who have undergone spinal fusion surgery to correct scoliosis. Some of us had a “C” curve and others had an “S” curve. **Between all of us, we experienced daytime bracing, nighttime bracing, no bracing, and in the end, spinal fusion surgery.** Our surgeries affected us physically, but they also had a huge impact on our families, our school life, and our daily activities. Although it may seem like a long, terrifying process, we all feel that surgery had a positive impact on both our physical health and our self-confidence. You can see the physical difference in the photos below, taken pre- and post-surgery.



When we first learned that we needed spinal fusion surgery, we connected with other girls and families who had already been through this experience. Each family we spoke to offered us so much great advice, which helped reduce our anxieties as the day of surgery approached. We wanted to pass this information on to other families to help make the journey through spinal fusion surgery a little bit easier.

Information for **PATIENTS & PARENTS**



It is really common to be nervous about undergoing spinal fusion surgery; however, we discovered many things that helped make the process a little easier and gave us some control over our hospital stay and recovery. We hope you find these tips helpful!

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Preparing for **SURGERY**

THERE ARE MANY THINGS THAT YOU CAN DO TO HELP MAKE YOUR HOSPITAL STAY MORE COMFORTABLE.

THINGS TO TAKE WITH YOU:

1 Items from home that give you comfort, such as your favorite blanket, stuffed animal, photos of family and friends, etc.



2 Face wipes and baby wipes to help you feel clean, since you might not shower the first few days you are in the hospital.



3 Chapstick and moisturizer.



4 Movies or electronic devices for entertainment.



5 A headset for your electronic devices.



6 Favorite snacks or drinks packed in a cooler to keep in your room.



7 A robe to wear when you are walking through the halls or having physical therapy.



8 Feminine hygiene products, as it is not uncommon for girls get their period right after surgery.



THINGS YOU CAN DO OR THINK ABOUT TO PREPARE FOR YOUR HOSPITAL STAY:



1

If you have long hair, braiding it into two braids on either side of your head will help keep it out of the way and keep it from getting messy while you recover.



2

If you enjoy music, create playlists of your favorite songs for pre-op and recovery to help pass the time when you are in bed.



3

Don't head out for a manicure or pedicure before surgery; your doctors will tell you not to wear nail polish because it interferes with the device that monitors your oxygen levels.



4

Be careful about texting or being on social media while on medications; you might not be thinking clearly, which can lead to saying things you normally wouldn't say.



5

You might be nervous as you head into the hospital to check in for your surgery, but don't worry, they can give you some medication to help you relax not long after you arrive.



6

Anesthesia makes you fall asleep very fast, and when you wake up, it will feel like no time has passed at all.



7

Your memory may be a little foggy after you wake up from surgery and throughout recovery.



8

You might be relieved to know that they put the IV's into your arm after you've been given anesthesia and are already asleep.

Recovering at Home

AFTER SURGERY

DURING YOUR RECOVERY AT HOME, THERE ARE MANY THINGS THAT CAN HELP YOU FEEL MORE COMFORTABLE. WE STARTED GATHERING THESE ITEMS IN THE WEEKS PRIOR TO SURGERY:

1. A **heating pad** will really help to relieve pain and discomfort
2. A **supportive chair** with armrests and a high back will help provide good back support as it is uncomfortable to sit on couches or other soft furniture for the first few weeks
3. **LOTS** of **bed pillows** (about 8) and/or a body pillow to help prop you into comfortable positions to make sleeping, sitting in chairs, and car rides more comfortable (*use rolled up towels if you need extra support*)
4. Something to help you communicate with caretakers who are in different rooms of the house (*a bell, cell phone, baby monitor, etc.*) since you will frequently need help repositioning and moving around
5. A **shower chair** for the first week at home because showering and washing your hair is hard if you are a bit lightheaded or dizzy from medications, and because you can't bend or twist (it doesn't take long to learn to shower without bending and twisting though)
6. If there are any items you need to prepare for your recovery, you may find it helpful to reach out to people in your neighborhood to see if there is someone who can loan you what you need, such as a shower chair (*Nextdoor.com, a social media app, is a great way to connect with people in your neighborhood*)
7. **Sweatpants, button-up shirts, and slip-on shoes** will make it easier to get dressed since your mobility is limited after surgery
8. **Lotion** can help keep your scar from getting dry, and silicone cream may help the healing process.



Helpful tips:

1. You will need to be repositioned in your bed every couple of hours throughout the day and night for the first couple of weeks at home. If you can push the side of your bed against a wall, you can use the wall to help support you. Pillows can be positioned between you and the wall to help prop you on your side into a comfortable position. Rolled up towels can also help provide additional support. Instead of rolling from your right side to your left side, you can start sleeping on your side with your head at the head of the bed, and then to reposition, sit up and then lay back down with your head at the foot of your bed. This makes repositioning much easier.
2. You may need help showering, getting dressed, or going up and down stairs for about a week or two. It is difficult to shower and dress when you can't bend or twist for several months, so you will need help from others at first. But you'll quickly adjust and find ways to make daily tasks easier to do on your own.
3. **You can work on building up your strength by walking in your neighborhood, or doing laps around department stores, grocery stores, the mall, etc. Once you start walking, you'll feel much better and quickly start to regain strength and stamina.**
4. It is not uncommon to feel very stiff early in recovery or for months after. Once your doctor gives you the go ahead, stretch as much as possible to gain back flexibility and strength.
5. You don't want to slip and possibly fall, so be conscientious of the weather when walking outside and don't wear socks on wood floors or stairs. We wouldn't bring this up if we hadn't experienced it ourselves!
6. You may find yourself feeling lonely during surgery and your recovery at home, but calling or using Facetime to keep in touch with your friends, planning to have some visitors, and going on little errands every day can help you stay connected and feel better. Be sure to pace yourself though because you may tire quickly and it can be easy to overdo it.
7. Don't be surprised if you experience nerve pain or numbness on some small areas of your skin, such as on your back or hips, even months into your recovery. This is totally normal, but be sure to tell your doctor about this or any other symptoms you are experiencing.



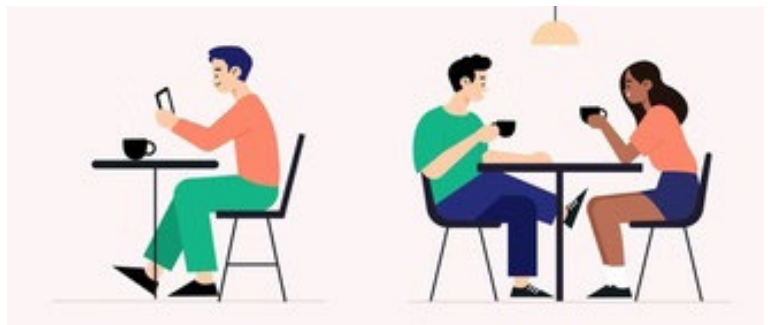


Surgery and School

1. It can be helpful to schedule your surgery around an existing school break, so you will miss less schoolwork.
2. Contact your school principal and counselor a few months prior to your surgery to begin the process of preparing for an extended school absence.
3. Some school districts have home and hospital instruction programs. You may be able to have a credentialed teacher come to your home through this type of program for tutoring so that you or your child can stay current on homework, quizzes and tests whenever possible.
4. Even if you have a coordinated home and hospital instruction program, talk to your teachers ahead of time about your plan to make up missed schoolwork so they are aware of your situation. You might be able to work ahead before your surgery so you don't fall too far behind.
5. Contact your school nurse and fill out appropriate paperwork to allow you to take medications during the school day, in the event you are still using non-narcotic medication when you return to school.
6. **Prior to surgery, collect phone numbers or email addresses** of at least one person from each of your classes so you can contact them if you have questions about any assignments.
7. Request a second set of books to use at home since you won't be able to carry a backpack with all your books for three months after surgery. You can use folders with sheets of paper at school and then transfer the sheets of paper into your notebooks at home so you aren't carrying too much during the day. You will have to use a small tote bag or other type of bag instead of a backpack. If you are in extracurricular activities and need to have equipment, an instrument, etc., with you throughout the week, recruit a friend who can carry those items for you.



8. Missed classwork can feel overwhelming to make up. **Two weeks post-surgery** is when we first started doing a little work every day, but this timeline is different for everyone. As soon as you feel up to tackling your make-up work, it can be helpful to create a list of all the assignments you need to complete and check each item off when you complete it to help you stay organized. Making a checklist like this can help you plan how much you want to get done each day and checking it off as you go will help you pace yourself and see how much you have already accomplished.
9. You might want to consider going back to school for half-days at first, and then eventually going back for full days. This can make the transition easier, since going back to school after surgery can be tiring.
10. Even if you feel you are ready to go back to school, consider taking an extra week off so you can fully catch up on all the work you missed and give yourself a little extra time to recover. It can feel less overwhelming to head back to school when you have caught up on the majority of your work, especially if you are in high school.
11. To help increase your stamina for long school days, **practice sitting in a kitchen or dining chair** for a long period of time in days leading up to returning to school.





The **BANDAGE**

A PATIENT MAY FEEL A BIT NERVOUS AND SCARED WHEN IT COMES TIME TO TAKE OFF THE BANDAGE, AND THE PERSON RESPONSIBLE FOR REMOVING THE BANDAGE MAY FEEL EQUALLY ANXIOUS!

WE WANTED TO GIVE YOU SOME ADVICE ON HOW TO MAKE THIS PROCESS AS PAIN-FREE AND EASY AS POSSIBLE:



1. Set aside an hour to remove the bandage. You won't be able to rip it off all at once; it's not like a Band-Aid that you can remove quickly. The tape holding the bandage in place is incredibly sticky, which is good because it keeps your wound nice and dry. But, it's hard to get off. Take your time to peel the tape back slowly.
2. Be patient with one another and know that your skin is healed and there is no chance of your caregiver ripping open the wound as they remove your bandage. Similarly, although it may feel like it, the tape will not rip your skin off either.
3. A wet cloth can be useful to help soften the adhesive.
4. To help reduce discomfort, use scissors to cut away small pieces of the bandage as you work on removing the entire bandage.
5. It can be helpful to watch a TV show or a movie while having your bandage removed to distract you and pass the time.
6. To ease your mind, the person removing your bandage can take photos of what they are doing and show them to you, or you can Facetime with them, so you can see the process of having your bandage removed.
7. Once the bandage is off, it is not uncommon for a thin layer of the gauze to remain stuck to your scar. It can be gently peeled off, or within a few days, it will gradually rub off on its own or come off when you shower.
8. Don't be surprised if you find a random stitch still in your skin.
9. A marker is used during surgery to mark certain areas on your back. It can take a couple of weeks for it to completely wear off.

Bandage



Gauze stuck to scar



Scar



Information for **PARENTS** and **CAREGIVERS**

OUR PARENTS WERE A BIT OVERWHELMED BY ALL THE THINGS THEY NEEDED TO DO TO PREPARE FOR OUR SURGERIES, HOSPITAL STAYS AND EXTENDED SCHOOL ABSENCES, BUT THEY DID THEIR BEST TO STAY ORGANIZED.

TO HELP YOU AND YOUR FAMILY ADD STRUCTURE TO YOUR JOURNEY THROUGH SPINAL FUSION SURGERY, WE COMBINED ALL OF THE THINGS THAT WORKED WELL FOR OUR FAMILIES AND CREATED AN OUTLINE BELOW. WE HOPE YOU FIND IT HELPFUL!



1 WEEK BEFORE SURGERY

1. Setting up a free **CaringBridge** webpage (caringbridge.org) can streamline the process of updating family members and friends regarding surgery and recovery.

It really helps relieve the stress of trying to keep up with phone calls and texts and allows space to focus on caring for your child.

2. Make sure your child's **bed is at a standard height**, so they will be able to sit down and get back up relatively easily. Your child will not be able to jump up if the bed is too high or bend down if the bed is too low.
3. Begin gathering everything your child will need or want in the hospital: clothes, blankets, movies, games, favorite snacks and drinks, etc.
4. Start **making plans** for family and friends to come visit while in the hospital (around day 3 or 4) and during recovery at home.

Note that the hospital restricts visitors during flu season. If your child has surgery during flu season, he or she might be able to ride in a wheelchair down to the lobby for visits with friends and family.

5. **Before surgery**, have your child practice getting in and out of a car without bending or twisting, since this process is difficult when your child first starts riding in cars.
6. If your child drives, the doctor may restrict driving for the first six weeks post-surgery. Start to make carpool or alternate transportation plans, if necessary.
7. **Cook** and **freeze** some meals ahead of time.

The first two weeks at home are exhausting for both patient and caregivers. If family and friends offer to help you out in some way, having them deliver meals can be a great way to stay connected to others and enjoy a meal you don't have to prepare.



1 DAY BEFORE SURGERY

1. Pack a bag for yourself with extra clothes, shower supplies, laptop, phone, wallet, and anything else you might want or need to have during your stay. Note that you can take a shower in your child's hospital room and the hospital provides towels.
2. There is a fold out bed so you can sleep in your child's hospital room; linens, pillows, and blankets are provided, so you do not have to bring these items.
3. Have your child pack a bag with button down shirts, slip-on shoes, tennis shoes, stretchy pants, cozy socks, shower supplies, feminine supplies, etc.
4. Pack a cooler and snacks for you and your child: waters, juice, Gatorade, crackers, fruit, pudding, Jello, etc. The hospital has a good selection of food to choose from, but sometimes you might want some comfort foods from home.
5. Wash your child's sheets and pyjamas, as they will need to be clean the night before surgery.
6. Your child will need to shower the night before surgery with a special antibacterial soap provided by your doctor.

DAY OF SURGERY

1. Be sure to bring your driver's license or ID with you, as you will need to show it each time you re-enter the hospital.
2. Take your suitcases, snacks, and everything else you or your child will need or would like to have during your stay.
3. If your child is experiencing a lot of anxiety as you are going through the check-in process, speak to your nurse about activities to help relax your child.

HOSPITAL RECOVERY



Epworth
Richmond

This information applies specifically to the Epworth Richmond

Information

Each room is equipped with a Point of Care (POC) an interactive in-room touch screen system, designed to provide information and entertainment during your stay. Your nurse will be your first point of contact during your stay, however should you feel the need to speak to someone in charge the contact number for the ward manager is 03 9426 6163.

Visiting Hours

1. Current visiting hours are 1000-2000hrs with a max of 2 visitors for 2 hours each day.
2. 1 allocated parent/carer may be with the child 24 hours a day, parents do not have to stay but if they wish to they are provided with a fold out bed and linen.

Meals

1. The child/patient will have access to order food on demand through our in room point of care system any time between from 7:00am – 8:30pm from a wide ranging menu catering for all dietary requirements.
2. Each parent staying will also be provided with meals, breakfast, lunch, dinner and will have access to a dedicated parent kitchen on the ward (tea, coffee, snacks) or to store special food brought in from home.

Entertainment / Wellbeing

1. POC system also offers Internet access, games, TV, streaming accounts, audio books and more.
2. Marine fish tank also located in the playroom for a good visual distraction as well as calming environment and each Thursday our therapy dog Koby visits the ward.
3. If your child is hoping for a little fresh air, it may be possible to spend some time outside, please coordinate with your nurse if this is possible.

Parking

The Epworth offers a week long pass where parents can come and go from the carpark, organised on admission but costs \$130, alternatively they can leave their car in the carpark for the entire admission and we can provide x1 discount card which makes it \$20 per day.

Discharge

All medications are signed off by the treating Dr and ordered from our pharmacist, they will come with a detailed medication plan explaining a little about the medications and how often they should be administered etc. please read this carefully and refer to the pharmacist should you have any questions about medication.

DAY BEFORE COMING HOME

1. Have a couple of bath towels that you can roll up and 3-4 pillows for the car ride home. You can put them behind your child's back and head to make the ride more comfortable. If your child feels nervous about riding in a car after surgery, breathing in essential oils placed on cotton balls may provide some relief.
2. Although none of us needed this, it might not be a bad idea to have a plastic bag in the car, in the event of carsickness.

AT HOME RIGHT AFTER SURGERY

1. Patients and parents should be prepared for 2-3 weeks of interrupted sleep, as patients will need to be repositioned frequently and medications need to be administered throughout the night. Our moms thought this stage of recovery was similar to when we were newborns. Thankfully, it only lasts a few weeks!
2. Create a chart to help keep track of medications and times to administer them. It can get confusing, especially when everyone is exhausted.
3. During the first week at home, days and nights tend to blur together. After that first week, it's helpful to try and get back to your usual sleeping habits.
4. Your child may want to continue laying in bed, watching TV or using his or her phone, sometimes late into the night, but it's helpful to start eating meals at regular times, push them to get out and about a little bit, and go to bed around their usual time, without any distractions, to start getting back to normal routines.
5. Surgery and recovery can feel lonely and isolating for both patients and caregivers, but this can be alleviated by going to big department stores (Target, Walmart, Ross, the mall, etc.) and walking laps to help increase your child's stamina, going to a favorite snack place, scheduling times for friends and family to visit, or doing other fun activities to increase everyone's activity level and help you all feel a bit more social again.

WEEKS AND MONTHS POST SURGERY



2 WEEKS — When narcotic pain medications are discontinued, pain may subside, but your child may still have general discomfort, which could result in needing to be repositioned throughout the night more frequently. *This is when we started to get caught up on school work (either at home or at school part-time), got out of the house to build strength and stamina, and began to socialize again. We were still pretty tired.*



4 WEEKS — At this point, your child will most likely feel much better overall, but may still have some discomfort sitting in chairs and other furniture at home or in chairs at school. We were back to school by this point, and able to keep up relatively easily.



6 WEEKS — A big milestone! This is when your child will really feel like him or herself again. Caregivers might start to feel 100% too, and life finally begins to feel normal.



3 MONTHS — Another big milestone as your child can enjoy getting back to most activities. And, your child can once again carry a backpack to school.

The anticipation of surgery was really overwhelming for us and for our parents, but once we had surgery, the recovery process seemed to move along very quickly. During recovery, have your child compare where he or she is today to where he or she was a week ago – your children will be amazed at how fast their bodies are healing.

We wish you well on your journey through spinal fusion surgery!

The logo consists of five horizontal bars of varying lengths, colored in shades of blue and green, stacked vertically to the left of the text.

setting
SCOLIOSIS
straight

Supporting Discoveries in Spinal Deformities

Setting Scoliosis Straight is a non-profit 501(c)(3) organization devoted to empowering families impacted by scoliosis through education, connection, and research.

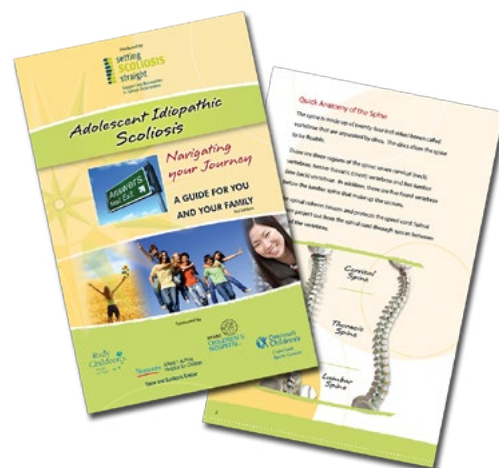
Our mission is to support discoveries and advance techniques in the treatment of spinal deformities in children and adolescents worldwide.



Visit our Website if you are interested in:

Downloading our FREE Scoliosis Handbook

Our handbook, "Navigating Your Journey" is a helpful guide for your family as you begin this journey together. The information we provided is from 25+ years of research and also includes important insight and wisdom from patients who have walked this path before you.



Watch our Multi-Chapter Infographic Videos

We have created a series of videos about Adolescent Idiopathic Scoliosis (AIS). These videos were created for you, to guide you as you start your journey.



Watch FAQ Videos from Renowned Surgeons

Finding out you or your child have scoliosis can be scary and we know you have a lot of questions. Watch our FAQ videos and hear from many renowned surgeons.



Read or Watch our Large Library of Patient Stories

Every patient has a story to tell. Watch inspirational interview videos of scoliosis patients to hear their stories and advice for newly diagnosed patients.



Learn More About our Power Over Scoliosis Event

Watch recorded presentations from our annual patient education events. Our events purpose is to educate and provide expert insight to patients and their families.





Thank you

Amanda Foster, Talia Sinder, Chloe Lopez & Sydney Deitz

for providing these helpful tips for the Setting Scoliosis Straight Foundation community and newly diagnosed patients and their families.

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