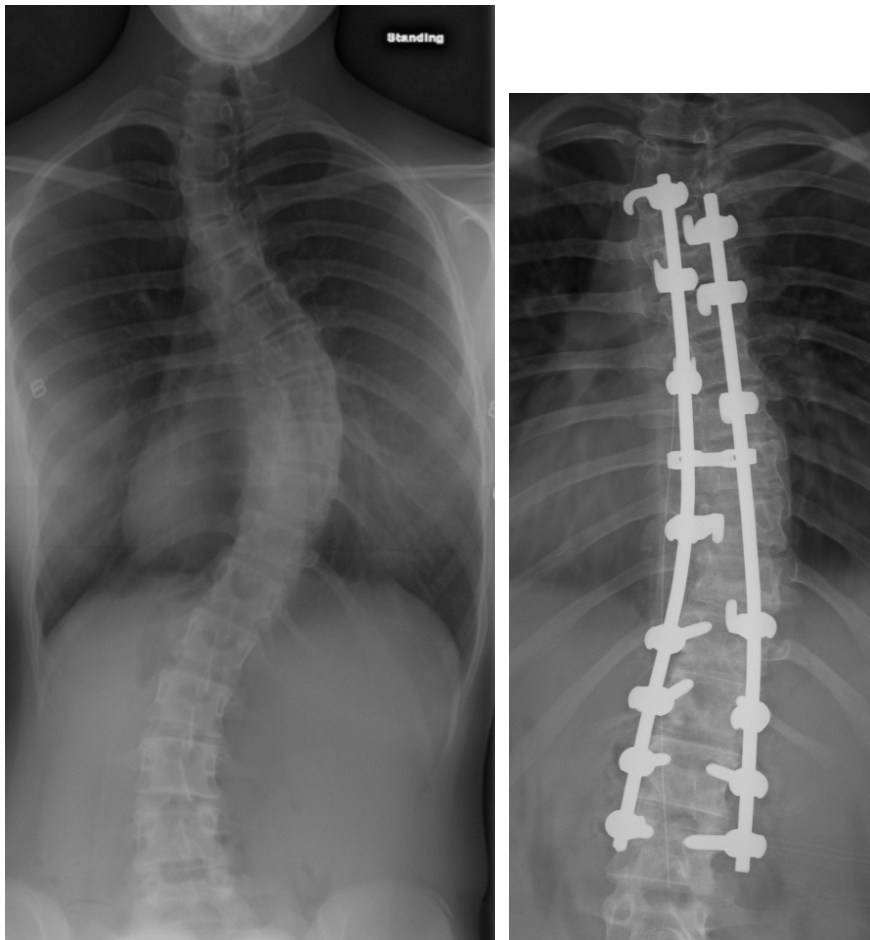


A PARENT'S GUIDE TO SURVIVING SCOLIOSIS SURGERY

By Joan Thomas



Scoliosis Surgery—from a Parent's Perspective

- *Sharing stories...how can our story help you?*
- *How surgery impacted our lives and that of our children*
- *How we supported our child and how you can too*
- *Preparing for the trip to the Hospital*
- *Surviving the surgery*
- *What I wish I knew then....*
- *What happens after the surgery?*



PREFACE



IMPORTANT NOTE:

This guide has been created for only those parents of children with scoliosis who have made the decision with their children and physician to proceed with the surgery. The purpose of this guide is not to advocate the surgery nor discuss alternatives, but to provide you with an account of our experience and tips that might help you feel better prepared for the hospital experience.

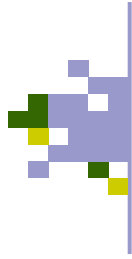
On the Cover: Jessica's back X-rays

Pre-op on 10/25/05, 54° curve (left)

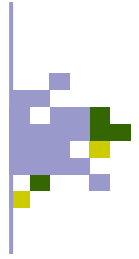
Post-op on 11/14/05, 22° curve (right)

ISBN 0-9785840-0-7

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SHARING STORIES...HOW CAN A STORY HELP YOU?



Every parent at one time or another says, “I wish I knew that before!” about something or another. Before my 14 year-old daughter’s surgery for scoliosis, my “about some things” were typical, such as knowing how much daycare cost before we bought a house with a 15 year mortgage!

This book focuses on the things I wish I knew before, during, and after my daughter’s back *surgery*. I emphasize surgery, because my experiences with major hospital trauma were limited to having two beautiful children by C-section eleven to fourteen years ago.

I’ve had other traumas in my life that resulted in my looking to support groups for help. Sharing of experiences (theirs and mine) helped me rebuild my strength and hope in living life. At times, words and slogans were like a lifeline for me. I wish I realized *before* the surgery, that listening to the experiences of other parents would help.

I didn’t think to look for a scoliosis support group (e.g., Scoliosis Association, www.scoliosis-assoc.org) on the Internet before the surgery because I didn’t realize how difficult would be to support a child undergoing a major surgery like spinal fusion.

A couple of months before the surgery, I connected with the doctor’s referral—a mother whose daughter underwent the operation four months before us. It turned out that she was my support. I was lucky to ask for a reference and even luckier to have connected with her.

I hope this guide will help you understand what kind of questions to ask the doctor and nurses—so you don’t need to rely on luck—when they ask: “*Do you have any questions?*”

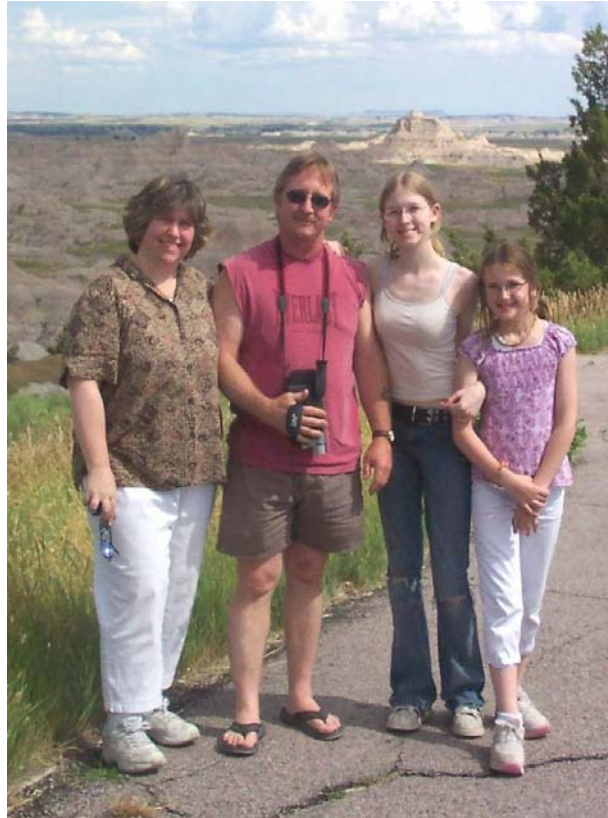
OUR FAMILY

Let me begin with a little background on our family. My husband, Wayne, and I have been married 16 years. I am a 44 year-old technical writer and a mother of two girls—Jessica, 14, and Megan, 11. Both girls have the same type of upper thoracic scoliosis.

SHARING STORIES...HOW CAN A STORY HELP YOU?

Joan, Wayne, Jessica and Megan Thomas (left to right) in the Badlands of South Dakota, July 2005. This was not only our first road trip, but just four months before the surgery.

We're smiling there and, now that it is over, we're still smiling!



This story is about our experience with Jessica and her surgery. Megan is still being monitored for her scoliosis. Unfortunately, her curvature has progressed from 25 to 41 degrees and she has just started her growth spurt. If it continues past 50 degrees, she will need the surgery.

Tip #1: If you have two children with scoliosis, don't do a checkup for your second child the day after surgery of your first for convenience. I did and it devastated me to hear she is much closer to the same painful experience as her sister.

In a way, having both children share the same office visits for checkups, brace fittings, brace wearing experiences helped create a special bond between them. If the girls didn't have each other, I would have searched for someone Jessica's age with whom she could commiserate, bond, and share her feelings. For example, someone from the Connecticut Teen Chapter of the Scoliosis Association.



HOW SURGERY IMPACTED OUR LIVES AND THAT OF OUR CHILDREN



Scoliosis impacted our lives before, during, and after the surgery. Each stage had milestones, but the week of the surgery and post-op week after surgery were the very hardest on me.

During the months before the surgery, we dealt with:

- Frequent office visits to check progression of their curvatures.
- Frequent brace fitting adjustments.
- Juggling vacation / personal time-off at work to accommodate the visits.
- Insurance claims.
- Lies and other means of resistance to wearing the brace (Finding the brace hidden in the downstairs closet was a real eye opener for me).
- Listening to complaints from a child who wanted perfect attendance at school, but couldn't because of medical visits.
- Clothing styles. Teen girls want to fit in and luckily for me (again), the baggy sweatshirt look was "in".
- Due diligence, i.e., getting a second opinion out-of-state to independently confirm our decision.

Making the decision for surgery took the most time. I think that is the case for most elective surgeries, however, this was the first major surgical decision for our child that we had to deal with, and it was difficult.

In Jessica's case, her curvature reached 48 degrees when she was about 13 (a year after her menstruation began). We were told that 50 is the point at which a surgeon would consider performing the corrective surgery for her type of upper thoracic scoliosis.

We followed our doctor's recommendation to give Jessica six months not wearing the brace (she'd been wearing it for several years) to see whether or not the curve would progress. It did.

HOW SURGERY IMPACTED OUR LIVES AND THAT OF OUR CHILDREN

It was mid-August 2005 by the time the decision was made to perform the surgery, and we could not wait until the next summer. At the time, I thought it was a worst-case scenario for timing—her starting high school and then immediately having surgery before Thanksgiving. But looking back now, I'm not sure that Jessica or I were really mentally ready for it when she was 13.

The next five months were a whirlwind.

See [Preparing for the trip to the Hospital](#) on [page 10](#) for our laundry list of activities.



As you can see, not all the impacts were negative.

Additional office visits helped us to stay close—as well as entertained!

Jessica is playing telephone with a blown-up surgical glove (the purple rooster already left the farm).



HOW WE SUPPORTED OUR CHILD AND HOW YOU CAN TOO



We have a relatively unique situation where both our children have scoliosis and are close in age. While Jessica's sister, Megan, could empathize with her situation, she still made it known to us when we didn't pay enough attention to her.

Focusing special attention was not the only way we supported Jessica, nor was support a one-way street.

We helped her by:

- Encouraging her to talk with someone her own age who underwent similar surgery to ask questions; we helped to make that connection possible.
- Telling her the truth—that it was not going to be easy—but not dwelling on it.
- Encouraging her to talk openly and directly with the doctor and nurses.
- Being prepared with comfort items, conversation, and hugs at any time!

She supported us by:

- Overcoming her fear of needles enough to tolerate blood tests; listening when we told her to relax so it wouldn't hurt as much (usually).
- Verbally assuring me on the drive home from the hospital that she was glad she had the surgery done (even though if she knew it was going to hurt so much she would have thought twice about it!).
- By saying she will be right by Megan's side every minute if she has to under go the surgery; she helped us show Megan just enough about the surgery to encourage her to continue wearing her brace.

Surgery was a growth experience for all. Not only did Jessica stretch 0.4 inch, but we deepened our relationship. I learned to really listen to her and let her make her own decisions and speak frankly. After all, as parents, we can say what we will, but what happens is ultimately up to them.



PREPARING FOR THE TRIP TO THE HOSPITAL



The following list contains activities that I focused on in August to get ready for the surgery in November. Hopefully this “packing list” will give you some ideas of what may be helpful to do before the hospital stay.

While I thought I was ready, there are a few important items that I wish I had included. For those, see [*What I wish I knew then...*](#) on [page 14](#).

- **Create a folder** for all email communications, statements, telephone and Fax numbers for doctors, teachers, etc.
- ***Insurance, Insurance, Insurance!***
Check with the insurance carrier(s) about issues such as your co-pay, second opinions, notifications, if you need to contact them before admission, and what any exclusions might be (like giving blood for your child). Luckily for us, we had insurance. Hospital costs billed for surgery alone were more than \$120,000.
- **Plan the date**
 - If surgery will be during the school year, determine a window of opportunity by reviewing the school calendar for when the marking period ends in relation to school holidays.
 - Notify the surgeon of the time period and find out what day of the week he performs surgery. *If you are lucky, it will be the same day you hope for!*
- **Save the date—in writing**
 - If you and/or your spouse work full-time, submit your time off requests. I was able to take seven days off but my husband could only take off one day. I had no idea how exhausting it was going to be at the hospital.

If possible, plan on two people for the time in the hospital and plan on someone at home full time for a few weeks.
 - Get a letter from the doctor for the school that outlines, when, how long, and what the needs are for your child. Ours, for example, stated the surgery date and expected length of time that Jessica would need a tutor. It also stated that she needed an extra set of books and a closer locker.

PREPARING FOR THE TRIP TO THE HOSPITAL

- **Arrange a pre-op release physical with your Pediatrician.** You will need to get sign-off from their medical doctor before starting the surgery and there may be blood work involved. Luckily, I kept Jessica's annual physical (scheduled in September) separate from the release physical. We found out early enough that she had anemia and that it could be treated before the surgery. To increase her iron, Jessica took three MegaFood Daily Foods Blood Builder tablets and ate lots of cooked spinach with beef.
- **Spread the word.** Meet with the high school Vice Principal or Dean of Students and/or Guidance Counselor and include the nurse on all communications:
 - Review the class schedule (Jessica dropped a video production class and took a modified gym class)
 - Relocate her locker
 - Request a second set of books for home
 - Arrange for a tutor
- **Cancel all unnecessary appointments** such as music lessons and notify any extracurricular activity teachers and/or coaches.



Our "Pre-Op" day included x-rays, a blood test, and general hospital visit.



PREPARING FOR THE TRIP TO THE HOSPITAL



- **Make arrangements for your other children** for school, walking the dog, etc. Having a daycare swap or taking neighbors up on their offers to help is a godsend.
- **Save extra money** for meals and hospital parking; Between our two cars, we spent \$28 a day on parking. Stocking the freezer before hand with small meals helps too.
- **Get a special gift or card** for each child and your spouse too before the surgery for after the surgery. You'll appreciate the sentiments more when you are home recuperating, than in the hospital.
- **Schedule a Pre-Op visit to the hospital** For more on this topic, see [*What I wish I knew then...* on page 14.](#)
- **Set up a phone chain** before you go. I drafted up a positive email, and asked my husband to send it when he got home that night. Have the telephone numbers of close family and friends, but let others pass the word along.
- **Arrange for post-hospital care**
Make arrangements to have a second person to help handle filling of the prescriptions, getting the car on the day you check-out, etc. so you can concentrate on packing up and absorbing release instructions.
- **Arrange to give blood**
See [*What I wish I knew then...* on page 14.](#)
- **Packing List**
 - **Pack light (use a rolling backpack)** Your child really only needs a bathrobe, underwear, hairbrush, toothbrush; have them wear button down loose clothes when they check in so they can wear them going home; leave the fluffy slippers at home, there won't be that much walking going on—yet!

For yourself, pack a hairbrush, toothbrush, deodorant, toothpaste, underwear, a towel and changes of clothes if you are spending the night.
 - **Bring a small notebook**
A notebook was helpful for me not only to record notes to the doctor, but as a way for me to talk to Jessica. Journaling is a

PREPARING FOR THE TRIP TO THE HOSPITAL

good way to vent the emotions that run high, especially those associated with the lack of sleep.

- **Bring your camera**
I felt awkward at first taking photos, but I'm glad now that I did. When your child is ready, they will want to see what they missed. In the meantime, heavy pain killers can be a blessing!
- **If you bring a cell phone**, don't forget the charger.
- **Bring a book, cards**, or something to keep your hands busy while you wait during the operation.
- **Find out what distracts your child most and bring that along.** For Jessica, her obsession was a portable DVD player with the Gilmore Girls TV series. Those DVDs were played almost constantly. Thank goodness for a private room! She also loves to read, although we brought books along, it was the DVD that saved the day.
- **Bring your folder!**

Here are a few personal notes for mothers about being emotionally ready for the trip:

- **If you like to have a neat house** and you don't have a maid service, be prepared to let it go for the week! Do what you can before you go, but you will need to focus all your energy elsewhere during the week at the hospital.

Before you leave for the hospital, be sure your child has button down silky PJs, comfy clothes, heat packs, and lots of pillows ready for when they get home.

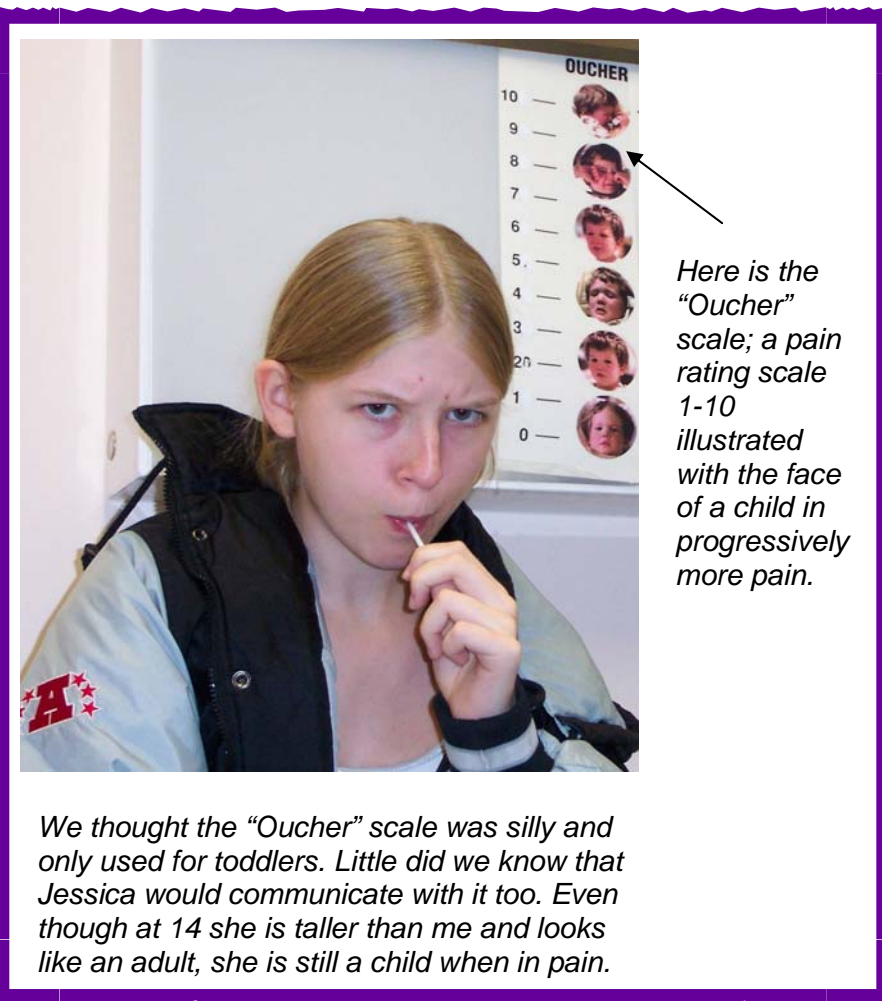
- **If you are a work-a-holic**, you'll have to let that go too. Even though



*Lego sculpture in the Atrium
at Yale-New Haven*

PREPARING FOR THE TRIP TO THE HOSPITAL

the hospital may have Internet access, you won't have time to leave your child's bedside and you'll be too exhausted to care when it's your turn for some sleep!



SURVIVING THE SURGERY



Jessica and Dr. Grauer just before surgery; we wouldn't see her smile again for about a week.

We were told that the length of every surgery is different; for Jessica it lasted 8 hours. She checked into the hospital at 6:30 AM on 11/14/2005, and was moved to Pediatric ICU by 4:00 PM in the afternoon.

The waiting room was noisy, so Wayne and I found a quieter waiting room nearby, one for cardiac patients. We checked in with the nurses every couple hours, always letting them know where we were.

I prayed, napped, tatted, and called my parents. Wayne and I walked the neighborhood and had lunch. It was a long day.

Jessica came out puffy from all the IV liquids, it made me feel sick to see her so swollen. Luckily for Wayne, he had experience with trauma and hospitals before and was strong.

As she was coming out of the anesthesia, she complained that she felt arched like the bed wasn't flat. She drifted in and out of sleep and cries of pain. She also expressed anger and fear about how much it hurt her. Luckily, 10 weeks after the surgery, she can say that she doesn't recall many details—just that it hurt tremendously.

The surgical stay was like seeing your child mature from an infant to a young adult all in one week. Every day, she got better and reached the goals set by the doctor. I kept a journal, it helped to pass the time and release some of my emotions.

Jessica spent two days in PICU and was transferred to the Adolescent wing at 1:00 AM. My husband and I took shifts sleeping and staying with Jessica—she did not want to be alone at any time.



SURVIVING THE SURGERY



We watched and asked the nurses about what was happening at every step. Two days after the surgery Jessica sat up for a few minutes in bed. The next day, a few steps to the bathroom. She was still very groggy, but she needed to get moving so her bowels could wake up again (so she could start on a clear diet and get off the IVs). I was surprised that she started menstruating as soon as the catheter was removed, but according to the doctor, it can happen because of the stress on the body.

On the sixth day, she made a one way trip using a walker to the gift shop and used a wheel chair for the ride back. That was an extreme accomplishment, we were all so proud and relieved. On the morning of 11/22, we all went home.

If we lived in an ideal world, and every surgery was the same (like Jessica's), I could say that for a parent to survive the surgery, you should remember these three A's:

- **Accept—and really believe—that the worst part of the surgery is the hospital stay and about a week at home.** Even with a child who, until then, I thought had a low tolerance for pain, every new day WILL bring new milestones. Remember and repeat this knowledge to your child often.
- **Ask for help.** Wayne and I split shifts so one of us would be with Jessica 100% of the time. It would have been easier for me if I had taken up my father's offer of help much earlier instead of thinking I could handle the situation on my own. By this, I mean:
 - Staying calm and positive so my child doesn't sense the fears I have.
 - Feeling frustrated especially as time went on, that I needed to sleep, but also needed to be up to help and comfort her.
- **Applaud their progress!** Keep reminding your child of the milestones they make— rolling over with less help (straight like a log), sitting up, walking, and eating ice chips or frozen Gatorade. After a few days, I found that encouraging her to brag about her progress to her grandfather, the doctor, nurses, and her friend Tracy, helped tremendously to get her moving. Moving up and out is the ultimate goal!

I was told two things by the doctors that I now believe as true—surgery is harder on the parents and that, as a parent, you'll probably be holding your child back while they heal more than they want you to!

WHAT I WISH I KNEW THEN...



Jessica is sitting up with Melissa, the Physical Therapist, for the first time.

It took a few days for Melissa to clearly see the blue of Jessica's eyes, because they were so swollen from IV fluid and pain medication.

This topic is probably the most important one for me. It's based on how I *think* I could have improved our experience and also serves as a reminder for me should Megan require surgery.

I wish I had:

- **Created a list or website of what my needs might be before I spread the news to the school, family, and friends.** That way when someone offered help, I could have taken them up on it at the time; I wasn't really prepared for loads of questions and offers of help. *Reading this booklet is a great start!*
- **Not wasted time and money trying to give blood for my child.** I was told Jessica might need a unit of blood and that she should give her own (she did have a one unit blood transfusion). Because of hospital and insurance policy, I spent \$185 for a private blood draw via the American Red Cross. It turned out that I was too anemic to give (as Jessica was), and later I was told that getting blood from a direct relation may not be best anyway.



WHAT I WISH I KNEW THEN...



- **Verbally told the front desk to page me if my daughter called while I was in the parent's room.** No child should ever feel their parent has left them.
- **Set aside more time to be at home after the surgery.** I didn't know it, but in Connecticut, the law states that a school tutor must not be in the house alone with the student. Luckily for me, my husband works from home four days a week, so we were able to obey that law (having walkie talkies helped for us stay connected for a few days too).
- **Thought about buying a large stash of disposable heat pads before surgery.** The disposable heat packs helped reduce swelling and gave Jessica freedom to roam, but it seemed we kept running out of them. I suppose having a couple wet and hot wash clothes (microwave one minute before putting into the bags) in plastic bags strapped to her waist probably would have worked just the same, but of course, not as convenient.
- **Realized that more than eight hours solo gets much harder after the third day.** Not only was I counting the minutes between medications or when a nurse would come, but sometimes, I counted the minutes for when Wayne would come to relieve me.
- **Taken better advantage of the "pre-op" hospital visit.** Jess should have tried out a hospital bed and had time to become familiar with the buttons, so it wouldn't have been so strange to her while under medication. I should have had a PT help me practice getting Jessica to sit up and out of bed so I wouldn't have felt so inadequate in the hospital. I also, should have toured both the ICU and the regular wings (and gotten any information sheets at that time).
- **Checked out the hospital website for a Visitor's Guide.**

I'm glad that I:

- **Realized early that physical therapy helps not only improve the physical condition, but also the mental state by giving confidence.** Without it, I would not have found out that massaging a scar with vitamin E not only can reduce scarring,

WHAT I WISH I KNEW THEN...

but breaks the adhesions under the skin to prevent stiffness and aches later on in life. Avoiding strong sunlight on the tender new skin of the scars for the first year was important too.

- **Kept the school physical separate from the “pre-op” release physical instead of combining the visits.** The routine physical showed that Jessica was anemic (common in adolescent girls, plus Jessica had significant weight loss the year before). We had enough time to improve the iron count in her blood. Healthy blood is very important for surgery.
- **Brought along her daily prescriptions.** Even though the hospital knew ahead of time of her needs, there was a delay in the pharmacy getting medication, so having a dose on hand was helpful.
- **Kept a journal with photos for her.**
- **Realized how motivating (and beneficial) incentives and bragging can be!** I saw the first real spark of my “old Jess” the night she first walked to the gift shop. I think part of that was to show off and have a shopping spree!



*A proud moment
in the gift shop.*

*Having
encouragement
from the girl who
already had the
surgery visit
helped give
Jessica the
incentive to walk
to the gift shop (in
addition to a blank
check)!*



WHAT HAPPENS AFTER THE SURGERY?



The drive home from the hospital was long. I tried to keep the ride smooth but needed to go fast enough to get her home before the medication wore off. We took Jessica to physical therapy a few times a week; after two weeks, she no longer complained of a “rough” ride.

I continued to record the time she took medications for a few days. Because I was still so tired, it was difficult to remember. My original thought was, when the doctor prescribed only a week of Valium (for spasms) and Percocet (for pain) was that it was not going to be enough. But, she actually transitioned to over the counter Tylenol before the pills ran out!

At home, she got lots of rest, but we also encouraged her to keep moving. Hot packs, an electric heating pad, pillows, friends, and of course, watching *Gilmore Girls* on her new DVD player helped her feel comfortable. I am so very proud of how she handled the pain of her first real bowel movement and trying to shield Megan from hearing her cry.

Recovery progressed quickly; every day continued to have new advances since the big day on 11/14/05:

- 11/23/05—She learned how to get out of bed alone with the help of silky PJs, a high backed chair, and tray table at the bedside. She was also weaning off of Percocet onto Tylenol.
- 11/24/05—Not only walked to bathroom independently, but went as well (first bowel movement with the aid of a stool softener for two days prior).
- 11/29/05—First meeting with the tutor; two hour per day sessions. She seemed hesitant and appeared to walk dragging her leg, so we asked the doctor to prescribe a few sessions of physical therapy to get her moving with confidence.
- 11/30/05—She dressed herself independently and obeyed the PT's advice about removing the steri-strips. It wasn't until then that she felt sure about letting us remove them (even though we were told by the doctor and nurses to let them fall off and not replace them). The scar line was healing shut and the skin was reddening as expected.
- 12/5/05—She started back to school for a couple of half-days a week, and stretched my patience by wanting to include an afternoon of debate club!

WHAT HAPPENS AFTER THE SURGERY?

- 12/8/05—Started 30 minute physical therapy sessions, twice a week. Concentrated on massaging the hip area to relieve the fluid (swelling) and strengthen the leg.
- 12/12/05—She had special permission to attend an all day field trip to a museum in NYC and loved it!
- 1/3/06—She started school full-time again! Jessica had to continue to meet with the tutor to tie up loose ends. Some things, like procrastination, don't change with surgery. That is when you know you are back to normal!
- 1/8/06—We finally had a chance to look back.

The doctor had given us a “before and after” x-ray the day after the surgery (front cover). He told us the correction reduced the 54 degree curve down to 22. She also stretched about 0.4 inch, so now she is 5' 7”, two inches taller than me. I felt the emotional impact of having my child be taller than me at 14 years old...well, *that is another story!*

Seeing the difference when she bent over and stood was awesome!



Just before surgery (left); Almost eight weeks after surgery (right).

There are three scars—A tiny drain line scar below and to the left of the main suture line. The wider short scar on the right hip bone is for the graft.

WHAT HAPPENS AFTER THE SURGERY?



Just before surgery (above); Almost eight weeks after the surgery (below)



I hope that by hearing our story, as a parent, you'll feel more prepared to embrace the experience as a positive one with less fear.



THANKS...



Everyone's support, thoughts, and prayers helped our family tremendously. My daughters surgery was definitely a humbling experience for me.

First, I'd like to thank my family for being so supportive and patient with me—my daughters Jessica and Megan, my husband Wayne, my parents and entire family...home and away!

I also want to thank:

- Our surgeon, Dr. Jonathan N. Grauer, MD, and all his staff for successfully performing the surgery with minimal scarring and paying attention to our pleas for her pain relief.
- The nurses and all who cared for us at the hospital, Yale-New Haven, in Connecticut, for providing me the incentive to create this guide to help others.
- Michelle Spray (<http://www.bookshelf123.com/>) for her inspiration and help to me for making this booklet possible.
- My many neighbors, friends, co-workers, TOPS members...everyone...for all their support and prayers for our family during this trying time.
- Jessica, for allowing me to share her very personal experience with others and for teaching me how to “let go” a little more!

Finally, a special thank you to Adell and her daughter Tracy, for their support and strength in sharing their own experience with Jessica and me.

To order this booklet, email:
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