Spinal surgery for children with neuromuscular disorders

An Orthopedic Center guidebook

Children's Hospital Boston

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Orthopedic Center, 2011

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Disclaimer

The information here is a general description of surgery and recovery expectations at Children's Hospital Boston. Your child's surgery will be personalized and may differ slightly from what is described here. Also, everyone recovers from surgery in their own way. You may find your child's recovery is somewhat different from what is described here. Please talk with your doctor about your child's particular surgery.

Contents

The spine

The spine is made up of many small bones called vertebrae, separated from each other by disks made of cartilage that act like shock absorbers. There are 7 neck (cervical) vertebrae, twelve chest (thoracic) vertebrae and 5 lower back (lumbar) vertebrae. At the very end of the spine are the sacrum and coccyx that help form the hip and pelvis area. The spinal cord passes through the vertebrae. Smaller nerves that go out to the rest of the body leave the spinal cord through gaps between the vertebrae.

Scoliosis

Scoliosis is a side-to-side curvature of the spine. Sometimes there is more than one curve. The spine can also twist, and that may cause one side of the chest or back to look more prominent than the other. Sometimes the patient can look like they have a “bump” on one side of the spine.

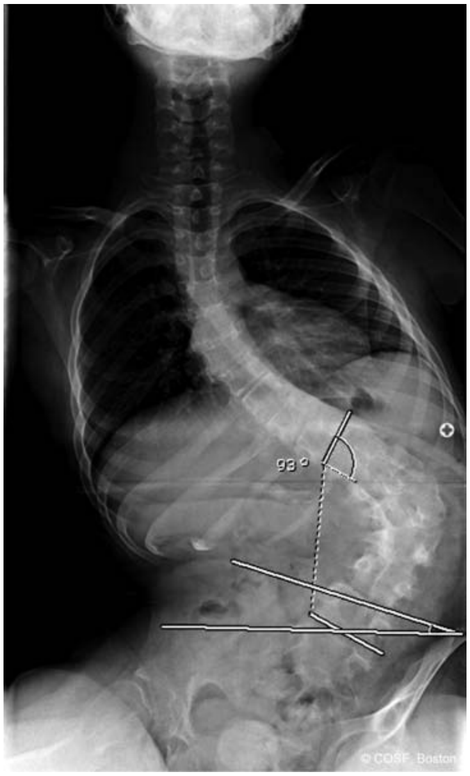
Neuromuscular scoliosis

Neuromuscular scoliosis is the term for a curve that occurs as a result of an underlying neurologic or muscular disorder. This kind of scoliosis could be caused by:

- cerebral palsy
- spina bifida (myelodysplasia)
- muscular dystrophy
- spinal muscular atrophy
- spinal cord injuries
- traumatic spine or brain injury

In some cases, the spine muscles get weaker over time, and that leads to inability to hold and support the spine in an upright position. The spine then begins to curve. In cerebral palsy (CP), spastic muscle activity can result in uneven pulling on the spine, causing a curve. With time, the curve may get larger, and could make sitting difficult, and may cause pain.

Bracing can help with support for a short time early on, but this type of curve will gradually get worse. The child’s hips may become uneven. This is called pelvic obliquity. Severe scoliosis can also make it more difficult for the child to breathe; because of the curve, the child has a hard time moving air into and out of the lungs.



neuromuscular scoliosis

Kyphosis

Kyphosis is another type of curve of the spine, this time going from the front to the back. Children with kyphosis have a backward curve in the spine, and can look like they have a "hump" in the middle of the upper back. This can also be caused by neuromuscular disorders (*see page 1*).

kyphosis

Lordosis

Lordosis is another type of front to back curve of the spine. This is a curve in the spine in the lower back, causing an increased arch in the lower back, or what may be called a "swayback" appearance. Again, this can be caused by neuromuscular disorders (*see page 1*).

lordosis

Surgical procedures

There are several types of surgeries designed for slowing down the progression of a curve or for correction of spinal curves in children with neuromuscular disorders. Your doctor will decide which option is best for your child, based on:

1. age
2. size and type of curve
3. general overall health of the child

What is a spinal fusion?

Some spinal deformities will continue to get worse if not treated surgically. Most operations are done to reduce spinal deformity and prevent worsening of the deformity. Some operations are done to relieve pain. Almost all spinal operations involve a spinal fusion.

Spinal fusion refers to the permanent stabilization of the vertebrae by stimulating the body to create bone and unite the separate vertebrae. Many operations involve the use of instrumentation (metal rods, hooks, screws, wires) to partially straighten the spine and help hold the vertebrae in a stable position while healing occurs. To achieve a fusion, bone chips are added to the surface of the spine. Over time, the bone chips and individual vertebrae fuse together into one solid, stable section of spine. The bone chips may come from the patient's hip (iliac crest), rib, or from the commercially prepared bone bank bone. Bone chips from the bone bank are carefully tested and treated to avoid the transmission of infection. Bone chips stimulate the patient's body to make new bone to help with the healing.

The fused portion of the spine hardens in the straightened position and prevents further progression of the deformity. Growth of the fused section of spine also stops, but the rest of the spine continues to grow, as does the rest of the body. It takes approximately 3–4 months for the vertebrae to stabilize after surgery and about one year for complete healing. Once the spine is healed completely, the instrumentation is no longer required, but instrumentation is almost always left in place unless infection or other complications occur.

Growing rods

In young children who are still actively growing, spinal curves get worse quickly. While we want to stop the curves from getting too big, we also want to allow as much growth as possible through the spine. Your doctor might suggest inserting growing rods. Extendable spinal rods, or *growing rods* are attached to the spine above and below the curve. This is done without doing a complete spinal fusion, to allow continued growth. The surgery to insert the rods is a moderate sized surgery. There is an incision made over the upper spine, placement of hooks or screws to attach to the vertebrae, creation of a local (small) spine fusion over several levels, and attachment of rods in between. The length of hospitalization when things go smoothly is typically 5 days.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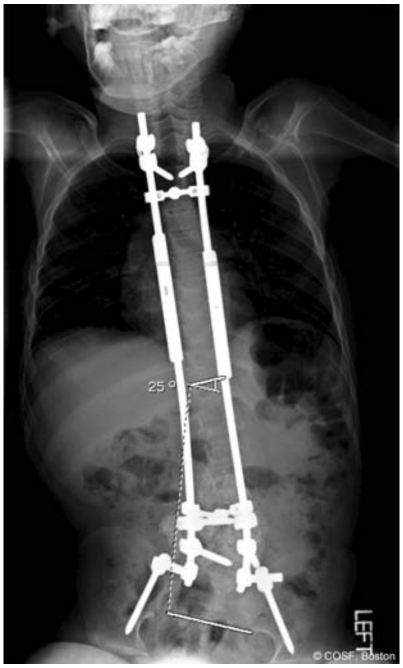
growing rods



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with growing rods extending to the pelvis

Your child will likely go to the ICU for monitoring and respiratory support for the first day or so. Once your child is able to breathe comfortably on his/her own, your child will be transferred to the floor.

From there, your child will have many goals to reach to be discharged. If your child walks at home, physical therapy and nursing will work on exercises and walking to help your child return to baseline. Your child's nutrition will be closely monitored. Many patients have a central line placed during surgery, a type of IV through which nutrition can be given to bypass the gut and allow the GI system to rest. It is typically a few days before your child will be ready to receive nutrition via G-tube or by mouth. The nutritionist will work with your medical team to create a bridge between IV nutrition and the usual means of nutrition. Once this occurs, pain control will switch from IV medicine, to medicine by mouth or G-tube. Respiratory function will also be a determining factor in discharge. Your child will either need to perform breathing exercises on his/her own, or if unable, will have treatments performed to relax lung tissues and to mobilize secretions. Typically, once dietary, pain, respiratory, wound and mobility issues have been resolved, your child will be ready for discharge. Your child may have temporary use of a brace for 3-6 months until the spine anchors become solid.

Your child will return for lengthening of the rods as a day surgery or overnight stay every 6 months or so. The length of the hospital stay depends on your child's health, comfort and recovery. Lengthening continues for several years, and is generally followed by a final spinal fusion and instrumentation once your child's growth is nearing completion. When the rods are outgrown in length, a part of them needs to be replaced. Usually, this can be done as part of a routine lengthening procedure, but may delay discharge a little bit. Sometimes the rods break and need to be replaced. Usually this can be done at the time of lengthening.

Anterior spinal release and fusion

Patients with severe curves associated with cerebral palsy, spina bifida, or other neurological conditions sometimes require an anterior release of the curve and may require an anterior spinal fusion.

During an anterior release and fusion, an incision is made along the side of the chest and abdomen. The surgeon will need to deflate one of the lungs to gain access to the front of the spine. Tight ligaments on the front of the spine are released. During a fusion, in some cases, a spinal rod and screws are placed in the vertebral bodies to stabilize the area while it heals, and bone chips from the bone bank are added to the vertebrae, to help the spine heal. A chest tube (drain) is placed next to the lung to help drain fluids so the lung can re-inflate properly. This is left in for 24-48 hours. Periodic X-rays are taken to assess the deflated lung's status. Once the output from the chest tube has decreased and X-rays have shown good re-inflation, the chest tube will be gently removed at the bedside and a dressing placed.

Sometimes, the doctor wants to release the tight ligaments, and then slowly stretch the spine for several weeks in the hospital, to make the spinal curves as small as possible before the final fusion. This means the doctor will do the releases, but he will not put the rods or bone chips onto the spine to fuse. The doctor will then admit your child to the hospital for a period of 2-6 weeks for halo traction. Your child will then return to the operating room for a posterior spinal fusion (*see page 7*).

before anterior spinal fusion

after anterior spinal fusion

Halo traction

Halo traction is a method for slowly and gently stretching the spinal vertebrae to get some correction of the curve(s) before surgery.


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Under anesthesia, a metal ring is placed around your child's head at the level of the forehead. Screws are gently placed on the sides of the forehead and behind the ears to attach the ring to the bones of the skull. Once it is placed, it is not painful for your child. The halo will need daily cleaning, which your child's nurse will teach to you. Typically, a day or so after recovery, your child will be placed into traction, the use of weights to gently stretch the spine into a more appropriate alignment. The traction may be setup in bed, in a wheelchair or both. The surgeon will decide whether your child needs to be in traction at all times or is allowed breaks. The surgeon will decide on a goal weight of traction for your child to reach. Each day, a few extra pounds will be added until this goal is reached. Periodic X-rays will be taken to assess progress. While in the hospital, your child is allowed to stand, sit in a special wheelchair designed for use with a halo, and may participate in some activities.

Intraoperative halo/femoral traction

For very large curves of about 100 degrees or more, one side of the pelvis can be higher than the other. This is pelvic obliquity. X-rays that are done before the surgery can show the doctor how flexible the spine is, that is, how much your child's spine will move with bending. The doctor will take advantage of a flexible spine to stretch it out in the operating room, before doing surgery, straightening the spine a little and bringing the pelvis down to a more level position.

The doctor may opt to place traction during the surgery. Under anesthesia, a metal ring is placed around your child's head at the level of the forehead. Screws are gently placed on the sides of the forehead and behind the ears to attach the ring to the bones of the skull. A pin will be placed just above the knee in the end of the femur (thigh bone), on the side of the pelvis that is higher. Then, small amounts of weight are added over time to gently and gradually stretch the spine. The doctor then performs a posterior spinal fusion. The traction stays in place during the surgery, and is removed in the operating room after the surgery is finished, while your child is still under anesthesia. Small Steri-Strips cover the wounds on the forehead and a dressing is placed on the leg.

Posterior spinal fusion with instrumentation

When a child has a neuromuscular scoliosis that has become worse the doctor may decide it is time for a posterior spinal fusion. This decision may also happen if a child presents initially with a very large curve, that may be affecting breathing, or when the child has finished use of the growing rods and it is time for the final step.

The goal of this surgical procedure is to stabilize the spine and partially straighten the most curved part of the spine. The incision is a straight line down the back of the spine. The doctor places bone anchors (screws, hooks or wires) into many of the vertebrae; the number depends on how much of the spine is included in the fusion. Rods are then attached to the anchors to help move it into a better position. The rods are slightly bent to follow the front to back curves of the spine.

The doctor straightens the spine only as much as is **safe**. Once the spine rods are in place, bone chips are placed over the vertebrae in the area of the curve that needs to be fused. This helps the body to heal the bones together. Once healed, the vertebrae will form a solid, stable section of spine. There will be no movement in the area of the spine that is fused, but your child can move above and below the fusion. In severe cerebral palsy (CP), children may have large curves, and the rods may be attached to the pelvis. This will limit range of motion in the lower back somewhat, but your child will be able to sit comfortably and have the usual range of motion at the hips. The instrumentation is usually left in place permanently. Most operations now use bone bank bone chips, but in some instances, bone chips from the patient's iliac crest (hip) are used instead.

Posterior spinal fusion is typically a large operation, taking most of the day. Many times, the procedure will start early in the morning and will finish at 7 p.m., or later. Your child will be admitted to the ICU after surgery where he/she will receive breathing support on a ventilator with the breathing tube still in place, and close monitoring. Your child's team in the ICU will work on weaning your child off of the ventilator, while also addressing fluid, nutrition and pain issues, blood loss and monitoring vital signs.

Once your child's vital signs are stabilized and he/she can maintain oxygen status without mechanical support, your child will be transitioned to the general floor. From here, your child will have many goals to reach to be discharged. If your child walks at home, physical therapy and nursing will work on exercises and walking to help your child return to baseline. Your child's nutrition will be closely monitored.

before posterior spinal fusion

after posterior spinal fusion

Many patients have a central line placed during surgery, a type of IV through which nutrition can be given to bypass the gut and allow the GI system to rest. Even if your child has a G-tube or eats by mouth, it is typically a few days before they will be ready to receive nutrition through these routes.

Your child's nutritionist will work with your medical team to create a bridge between IV nutrition and the usual means of nutrition. Once this occurs, the treatment of pain control will switch from IV medicine, to medicine by mouth. Your child's respiratory function will also be a determining factor in discharge. Your child will either need to perform breathing exercises on their own, or if unable, will have treatments performed to relax lung tissues and to mobilize secretions. Typically, once dietary, pain, respiratory, wound and mobility issues have been resolved, your child will be ready for discharge.

Typical length of stay	
Insertion of growing rods	5 days
Lengthening of growing rods	1-2 days
Anterior spinal fusion only	5 days
Posterior spinal fusion with or without intraoperative traction	7 days
Anterior spinal release admit for halo traction, and posterior release	3-6 weeks

Preparing for surgery

Preoperative (Pre-Op) clinic visits

An appointment will be made for your child with the Pre-Op clinic and with the Orthopedic Center before your child's surgery. Our surgical coordinator will make this for you. You and your child will meet with the orthopedic mid-level provider (MLP) in the Orthopedic Center. The MLP will explain more about your child's surgery and answer any questions you may have about your child's hospital stay and recovery. The MLP will ask questions and review your child's health history, perform a physical examination, and discuss bracing and/or casting. During your preoperative visit, you also may have X-rays or other tests done. Your child may have blood tests done if the surgeon has requested them. You may sign the consent form for the surgery at this visit.

You and your child will also meet with the MLP in the Pre-Op/Admitting Clinic. The preop MLP will take a complete health history and do a physical exam. The MLP will make sure all of your child's physicians know about the upcoming surgery and collect all recommendations. The MLP will review all of your child's medications. **Please tell the MLP if your child has any allergies, or if your child is taking any herbal supplements.** You and your child also will meet with the anesthesiologist, to talk about the pain medication your child will receive during and after the surgery. The preoperative day is often a long one. It is a good idea to bring snacks and drinks and things to do to fill the waiting time.

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Will blood be needed?

All patients lose some blood during spinal surgery because of rich supply to tissues and bones. Lost blood is collected in the operating room through a cell saver system, filtered, and can be given back to your child through the IV line during the surgery. However, if patients will need additional blood transfusions during or after surgery, they have ready access to the Children's Hospital Boston blood bank.

Medications

It is very important that you tell your doctor or mid-level provider about all medications your child is taking. Be sure to include all herbal remedies, prescription medicines, including any form of birth control pills, patches, etc., as well as over-the-counter medicines. Bring all the bottles with you to your child's pre-op visit and have them with you on the day of the surgery.

If you are planning to have your child receive any vaccinations, including H1N1 or flu vaccine, these must be given no closer than one week (7 days) before the scheduled surgery.

Medications to avoid

Some medications affect your child's blood and may cause excessive bleeding during an operation. So, **certain medications should not be taken for two weeks before the surgery.** These include:

- aspirin
- ibuprophen
- Advil®
- Aleve®
- Motrin®
- Nuprin®
- Naprosyn®
- some herbal remedies

Many medications may contain one of these ingredients. If you are unsure about whether your child can take a medication, talk with your nurse or doctor. Your child may use Tylenol® (acetaminophen) during the two weeks before the surgery.

Prescription medications

Be sure to tell your doctor or mid-level provider if your child is taking any prescription medicines. Any birth control pills or patches should be stopped one month before the surgery because of the risk of blood clots.

Constipation

If your child is constipated regularly, your doctor or nurse may suggest medication to help make your child regular before the surgery, to help avoid problems with constipation after surgery.

Eating and drinking guidelines for surgery

For your child's health and safety, eating and drinking (including nutrition via G-tube) are not allowed for a certain period of time before surgery. It is important that you and your child follow these directions. **The surgery will be cancelled if you do not follow these guidelines.**

Do not feed your child a large meal the night before surgery, since the digestive system will slow down after surgery. All that food from a big meal may make your child throw up after waking from anesthesia.

Eating and drinking guidelines for surgery	
clear liquids	stop 2 hours before surgery/procedure
breast milk	stop 4 hours before surgery/procedure formula
formula: children over the age of 1 year must stop formula 8 hours before surgery/procedure	stop 6 hours before surgery/procedure
solid food: including candy, gum, non-human milk	stop 8 hours before surgery/procedure
thickened formulas including commercial ones such as AR (which is added to rice).	stop 8 hours before surgery/procedure
G-tube formula feeding should be stopped after midnight, except for children under 1 year of age who may continue G-tube formula for up to 6 hours prior to the time of surgery/procedure.	

Visitors

Family members are welcome to visit anytime. Hospital visiting hours for friends are from noon to 8:00 p.m. Family members must wear a visitor's badge which they will receive at the time of the child's admission — or from the Parking and Transportation Office, located on the ground level of the Children's Hospital Boston parking garage at 283 Longwood Avenue, Monday–Friday. Visitors under the age of 12 must be screened for exposure to any known contagious diseases, such as chicken pox or measles, before coming to inpatient floors. Visiting children will be given a dinosaur sticker to be worn at all times when they are in the hospital to show they have been screened. One parent may stay with the child overnight. In the room, there is a chair that opens into a cot. Your child will probably have a roommate. You may want to discuss visiting and overnight plans with friends before your child's hospital admission.

View more information on your child's hospital stay at www.childrenshospital.org/ortho/visit

Please note: the above information is for Children's Hospital Boston only. If your child is having surgery at another facility, please contact them directly for visiting rules.

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The day of surgery

Pre-Op Clinic

On the morning of surgery, return to the Pre-Op Clinic ninety minutes (1½ hours) before the time your child's surgery is scheduled. The nurse or mid-level provider (MLP) will recheck your child's temperature, heart rate, breathing, and blood pressure and ask when he/she last ate or drank. Your child will change into hospital pajamas. Then, you and your child will be brought to the Pre-Op holding area (near the operating room).

Pre-Op clinic

Pre-Op holding area

You will talk to a nurse from the Pre-Op holding area, the nurse from your child's operating room, your child's anesthesiologist, and your child's surgeon. The anesthesiologist may start an IV. If your child is having blood drawn on the day of the surgery, it may be drawn at this time. If your child is difficult to start an IV on, or is very anxious, the team may wait until your child is asleep before starting the IV and drawing the blood. The surgeon and the nurse will confirm with you the exact operation that your child will have. Many people will verify this with you before the surgery. This is part of the patient safety guidelines in place at Children's. The anesthesia doctor may give your child some medicine through the IV to help your child relax.

Pre-Op holding area

Family waiting area

After your child is taken into the OR by the anesthesia team, you will be escorted to the Family Waiting Area. You can wait there until you can visit your child in the recovery room immediately after the surgery.

Either in the Pre-Op holding area or in the family waiting area, you will meet the surgical liaison nurse. During surgery, the surgical liaison nurse will check with the operating room every ninety minutes and give updated information to you. You may also leave a cell phone number with the liaison nurse since the duration of the surgery is somewhat unpredictable. When the surgery is done, and the child is brought to the recovery room, the surgical liaison nurse will bring two family members at a time to see the child.

family waiting area

The operating room

operating room

In the operating room, your child is covered with warm blankets and given intravenous medication to help him or her relax. The room is warm, soft music is playing, and your child is surrounded by people whose only job is to take care of him or her. Sometimes parents choose to stay with their child until he or she is under anesthesia and asleep. This is your personal choice. Anesthesia is given through an IV. Your child will breathe oxygen through a soft mask and drift off to sleep. When your child is under general anesthesia, a catheter will be placed into his or her bladder. An additional IV may be inserted as well.

Once your child is ready, the operating room staff will turn your child on to his or her stomach. Soft cushioning will be placed under the chin and the chest to help prevent pressure areas. Next, the entire back will be cleaned with an antiseptic solution. After the surgical drapes and towels are placed around the surgical area to keep it sterile, the surgery will be performed.

It is usually about 60-90 minutes from the time your child enters the operating room until the operation starts. Depending on the complexity of the surgery, 3-12 hours may pass from the time you leave your child until you meet him or her again in the recovery room. Only a portion of this time is spent doing the actual surgery. Some time is spent with preparation, X-rays, etc. Once the surgery is completed, the incision(s) will be closed with dissolvable sutures, a type of glue may be placed on the skin, and a sterile bandage will be applied.

There may be a foam padding placed on the back around the incision to help prevent pressure to the area. Then, the operating room staff turns your child over again to lay on his or her back for recovery. After the surgery is finished, your child will slowly become more awake as the anesthesia wears off. Once he or she is alert, your child will be lifted onto his or her bed, and placed on his or her back. You will see your child in the PACU (Post Anesthesia Care Unit).

The Post Anesthesia Care Unit (PACU)

Your child will be transported to his or her bed in the post anesthesia care unit (PACU) directly after surgery. He or she will be groggy and sleepy. Sometimes the child does not really remember the PACU. A nurse will check your child's blood pressure, heart rate, breathing and circulation. He/she may have a mask blowing a cool oxygen mist until your child is completely awake. If your child has pain, the nurse will give some pain medication through the IV. Your child's IV and urinary catheter will stay in place for several days. **Your child will have at least one IV catheter that will stay in for the whole time he or she is in the hospital.**

Your child may have two visitors at a time in the PACU. After a stay of 2-3 hours in the PACU, your child will be transported, in the bed, to the inpatient surgical specialties unit for the remainder of your stay.

The Intensive Care Unit (ICU)

Some of our more complex children may be transferred to the Intensive Care Unit (ICU) for a time. You can go with your child to the ICU and stay there with him or her. Children who will be spending time in the ICU in the immediate postop period may continue to have the breathing tube in place (intubated) for some time after the surgery and be sleeping (sedated) longer to allow the child to become stable and let him or her rest comfortably. The decision to remove the breathing tube and any other care is the responsibility of the ICU team. A central venous line may be used to give nutrition while the child is in the ICU. This allows the digestive system to relax and stabilize. Depending on your child's recovery, you may be transferred to the inpatient surgical specialties unit, or you may continue to be in the ICU, and can be discharged from the hospital from there at the end of your stay.

The Surgical Specialties Unit

After you have arrived on the surgical specialty unit, you will meet your child's nurse and get settled into your room. Your child's temperature, heart rate, breathing and blood pressure will be checked. All rooms have a TV and VCR. Most patient rooms are double occupancy. A child life specialist is available on the unit to provide videos, computer games, arts and crafts, and other activities. *Additional information is available at www.childrenshospital.org/pf*

Chest tube

Usually with an anterior spinal release, your child will need a chest tube to drain the fluid that collects outside the lung and to keep the lungs working properly. If there is a chest tube it is put in during the operation and your child will not feel it. The chest tube is covered by a bulky bandage and is attached to a plastic container, which collects the drainage. It remains in place for about two days after surgery. A doctor will remove the chest tube.

Wound drainage

If your child had a drain placed in the surgical wound, it will be removed 1-2 days after surgery. This is not painful.

Urinary catheter

While your child is asleep during the surgery, a nurse in the operating room will put in a urine tube known as a catheter. Your child will not feel this being done. The catheter allows for urine to drain through a tube and into a plastic bag. The nurses will measure the amount of urine produced. A few days after surgery, the tube is removed. Removing the tube does not hurt, but may feel a little odd. If your child is normally diapered, he or she can continue with this. A few hours after the tube is removed, your child will need to go to the bathroom.

Turning and positioning

Every few hours, your child will be repositioned to help decrease pressure areas on the skin. The child also may be on a special mattress. There should be support under the heels to prevent pressure sores. The nurse will help reposition your child in the bed. Most children are in bed for 2-3 days after the surgery, depending on the type of surgery they had.

Eating and drinking

The operation, anesthesia, and medications can make your child's digestive tract slow down for several days, which decreases his or her appetite. At first, the nurse will give your child water or ice chips. Go very slowly. Remember, your child's stomach has been empty and will be slow to wake up. If your child has a G-tube, nutrition will be restarted slowly as bowel sounds return. Sometimes, children need to receive nutrition through an IV line until they are ready, this is called *total parenteral nutrition* (TPN). Once your child is drinking, he or she can start taking pain medication by mouth. He or she will gradually be able to eat regular foods in small amounts. Don't worry if it takes several weeks for your child's appetite to return to normal. Your child may be constipated at first. Your child will be given medicine to help with this. He/she needs to have a bowel movement before you leave the hospital.

Dressings

Your child's first surgical dressing may or may not be changed before you go home. The dressings don't need to be changed routinely, and often will not be removed until the first postop visit. If the dressings do become dirty, or begin to come off on their own at home, they can be changed. Once home, if the dressings become soaked with a lot of drainage from the wound, call the Orthopedic Center at 617-355-6021 as soon as possible.

It is very important to keep the incision and the dressings on the lower part of the incision clean. If the dressings do become contaminated with stool or urine, they need to be changed. **We take this very seriously as the risk of infection is very real.**

Pain medication

Your child will be visited by a group of pain treatment specialists. These doctors and mid-level providers will assess how your child is feeling. When able, they may use a *pain scale*, which may be a number scale (0-10) or pictures of faces. If your child is not comfortable, tell these doctors, nurses or mid-level providers so that changes in pain medications can be made. Parent input is important, as you know your child best, and are the best at reading their responses.

The amount of pain medication is based on your child's weight, age, diagnosis, and type of surgery. Sometimes parents are worried that pain medication may be habit-forming and may try to limit the use. It is unlikely that your child will form dependence as long as he or she is taking the medication as prescribed for the pain. Pain medication will help your child change positions easier and breathe more deeply after surgery. Your child may be given a medication to help stop muscle spasms. This is an important part of your child's pain control plan, and should be taken as directed. As always, if you have any questions or concerns, please ask the doctor, nurse or mid-level provider caring for your child.

Once your child begins to drink and eat small amounts of food (or starts to take food through his or her G-tube), the IV may be removed. He/she will take pills or liquid medication instead of using the IV medication for pain. Except for the tug of the tape, IV removal is not painful.

Potential surgical complications

As with any surgery, a major spine surgery involves some risk of complications. Though not frequent, complications include surgical wound infection, injury to major nerves or blood vessels, and non-union (failure of the bone to heal). Your doctor will discuss the specific risks associated with your child's surgery with you as part of the planning process and again at the preoperative visit.

Physical therapy after surgery

Following spinal surgery your child may be referred for physical therapy while in the hospital. All children who undergo a spinal fusion will be referred. Some, but not all, children who have placement of growing rods will be referred depending on their needs. Some children have difficulty clearing their own pulmonary secretions in hospital right after surgery, so chest physical therapy will be done to help loosen and mobilize the secretions. This procedure involves clapping (percussion) over the child's lungs to loosen the secretions and stimulate a cough.

The physical therapist will also assist with transfers to a wheel chair, and assist with positioning in the wheel chair. If your child has a halo inserted they will be transferred to a special wheel chair designed to support the halo. If adjustments are needed to your child's own wheel chair they will be made if possible. Range of motion exercise will be performed to maintain your child's flexibility during their hospital stay. For children who are walking pre-operatively, the therapist will work with your child to restart walking using any necessary aides (walker) to return them to their baseline.

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Going home

Discharge

Your child will be discharged when he or she is able to sit comfortably. Your child also must have good pain control on medicine by mouth or through a G-tube. Your child should be eating normal food or taking nutrition via G-tube before discharge, and should have a bowel movement before going home.

Your child's nurse and mid-level provider will give you important instructions on how to manage diet, how to care for the incision, what problems to watch out for, and who to call with questions. Your surgeon will tell you when you can expect to go home. **Discharge time is 11 a.m. Please arrange in advance for your transportation home.**

Prescriptions

Before you go home, you will receive prescriptions for medications for pain and spasms your child will need at home. These prescriptions should be filled before you leave the hospital. Some of these medications **cannot** be called into your pharmacy. The pharmacy will need the original prescription. It is very important that you call for refills on medications several days before you run out.

Transportation home

When planning your transportation home from the hospital, consider what mode of transportation will be the most comfortable for your child, and how he or she will fit into a car or car seat. The **Inpatient Child Passenger Safety Program** has several different types and sizes of car seats available for all ages for rent or purchase, and they are available to talk with you as an inpatient.

Before you go home

- **Be sure you have filled your prescriptions.**
- Confirm that a follow-up appointment with your orthopedic surgeon or mid-level provider has already been scheduled.

While your child is in the hospital, a case manager will help plan your child's discharge. If you will need a wheelchair, hospital bed, commode, walker, or any other equipment, the case manager will rent it for you. He/she will also schedule visiting nurse services if needed, and home physical therapy, and blood draws if needed. If you think you will have difficulty caring for your child in the initial days after the surgery, please let us know and we can discuss options that may be available to you.

Return to school

Your child will feel tired, and be uncomfortable for a few weeks. If only growing rod lengthening is done, your child may return to school in 1-2 weeks. On the other hand, a posterior spinal fusion will keep your child out of school for about 6-8 weeks. A tutor form can be written. If your child continues to need narcotic pain medications, he or she is **not** ready to return to school. Check with your school ahead of time to see how comfortable they are with the return to school, and work with them to set up transportation and help for your child during the school day. If your child gets occupational, and speech therapy in school, this can generally resume at home as he or she heals. **Physical therapy will not start again until the doctor gives you the official physical therapy order.** Do not allow your child to resume any activities until the doctor tells you it is time.

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Resources available for families

As you plan for surgery, there are many details to keep in mind. Social workers are available to facilitate some of the non-medical issues related to admission and post-operative recovery. Social workers are part of the multidisciplinary health care team, and work as licensed professionals in providing a spectrum of psychosocial services to enhance the quality of care. Adjustment to illness and, specifically, to hospitalization, is very stressful. It is important to plan ahead, not only in terms of medical needs for recovery, but also for general support for the patient and the caregivers. Here are some of the resources available during admission to best help during this stressful time:

- Care Management Center – Discharge planning and equipment needs.
- Center for Families –Library, internet access and general resource for program to help families, including parking program for income eligible families.
- Chaplaincy/pastoral Care – Provides spiritual support, services and resources.
- Child Life Specialists – Developmentally appropriate activities for patient; facilitate tutoring during admission.
- Psychiatry consult service – Assess and work with patient during stressful admission to address overall mental health and coping.
- Social work (inpatient) – Provide support to family during admission; help with problem solving and community resources.

Before and after admission, questions may arise about resources such as finances, guardianship, education, transportation and adjustment/coping. Some further resources to utilize:

- Financial counselors – Can address insurance questions specifically around Mass Health coverage and applications.
- Social work (clinic based) – Ongoing support, resource needs assessment, coordination of services.

Transportation is an often identified issue following surgery. There are several options:

- PT1 (prescription for transportation through MassHealth) – If patient has Mass Health Standard, a PT1 can be submitted for travel. PT1 can only be used for appointments (medical/mental health, physical therapy, etc).
- MBTA RIDE – One-to-two months prior to surgery, application should be submitted for this service that provides door to door transportation to make the T handicap accessible. RIDE can be used within eligible Massachusetts towns; not limited to appointments.
- Reimbursement – Mass Health will reimburse for travel to and from appointments; limited amount per mile. This is relevant for all appointments, not specifically for pre and postop.
- Other states (including NH) also have reimbursement programs.

For additional resources please visitation is available at www.childrenshospital.org/pf

Frequently asked questions

What will my child's appetite be like at home?

Your child may not eat as well as usual for a week or two after spinal surgery. Try small meals and frequent snacks every 2-3 hours. G-tube feedings should have resumed before discharge. Constipation may be a problem after surgery because of side effects of pain medicine, and changes in diet and activity. Your child may be given medication to help prevent this, and lots of liquids or any foods that help your child be more regular can be used.

When/how does my child shower at home?

The dressing will stay on until the first post-op visit. Your child may shower with the dressing in place as it will be covered with a waterproof clear dressing If the dressing gets loose, reinforce it with tape. But do not remove it.

Does the incision need any special care?

Check the skin on your child's back at least once a day until it is fully healed. Check for signs of infection which are increased redness, swelling or tenderness; yellow or green fluid (or pus) on the dressing or the skin, an unusual smell, or a fever higher than 101 degrees Fahrenheit (by mouth). **If you notice any of these signs of infection notify the orthopedic surgeon or the nurse practitioner in the Orthopedic Center at 617-355-6021.** The incision will be covered with small strips of tape called Steri-Strips. Usually, there are no sutures or staples that need to be removed.

Will my child have any discomfort at home?

Your child may still be a little uncomfortable after you go home. Give the pain medicine as prescribed by your doctor. The medicine will be in pill or liquid form. As time goes on your child will need the pain medicine less often as he/she feels better.

When can my child return to school/day-care?

Talk to your doctor about when your child may return to school or day-care. You will need to arrange for a tutor at home for four to six weeks until your child is strong enough to return to school. The Child Life Specialist on the surgical specialties unit will help you arrange for home tutoring if it has not already been arranged through the Orthopedic Center.

What should I do if I have questions or concerns?

If you have any questions or concerns after you return home please call your orthopedic surgeon or nurse practitioner in the Orthopedic Center at 617-355-6021.

Will my child need a brace after the surgery?

Generally, patients do not need a brace. Instrumentation acts as an internal brace.
Your surgeon decides if your child will need a brace after surgery. If your child needs one, your child will be measured and fitted for the brace during the hospital stay. The nurses will spend time with you teaching you about the brace before you go home.

Glossary of spinal deformity terms

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Anterior spinal fusion – A fusion performed on the front of the spine, usually involves replacing inter-vertebral discs with bone.

Autologous blood donation – Blood donated by the patient for use by the patient during or after spinal surgery.

Bone age – An X-ray of the hand and wrist is compared to the average appearance of the bones at different ages. An estimate of remaining growth is obtained.

Bone bank bone – Bone graft obtained from cadaveric donors.

Bone graft – Pieces of bone used to create a fusion. Bone graft is obtained from the patient's iliac crest, rib, or from the bone bank.

Brace – A semi-rigid plastic device, which pushes on muscles and ribs near the spinal column. The brace is designed to decrease the abnormal spinal curvature and improve posture while worn.

Directed donor blood – Blood donated by family or friends for use by a patient during a future operation.

Disk – The inter vertebral disk is a strong, rubbery and gelatin – like structure which normally separates the individual vertebral bodies and allows movement between them. Disks are usually removed from the portion of the spine undergoing anterior fusion and replaced with bone chips to create a fusion.

Fusion – A continuous mass of bone which solidifies and immobilizes the desired part of the spine. A fusion is created by adding bone graft to the surfaces of vertebra and then immobilizing that part of the spine with instrumentation or with a cast. A solid fusion does not bend or curve more as time passes.

Hook – A hook is a type of spinal anchor that takes hold of the vertebra.

ICU – Intensive Care Unit.

Iliac crest – The iliac crest is the large flat portion of the pelvis bone from which bone graft is taken.

Incision – The cut made through the skin for the purpose of an operation.

Instrumentation – The metal rods, hooks, screws, etc., which are attached to the spine to change spinal shape and immobilize the spine while fusions occurs.

IV – The intravenous line, which delivers fluid and medicines through a hollow tube inserted in a vein.

Kyphosis – Curvature of the spine with the curve pointing toward the back of the body.

Lordosis – Curvature of the spine with the curve pointing toward the front of the body.

Orthosis – A spinal brace.

PACU – Post-anesthesia care unit – also known as the recovery room.

Posterior spinal fusion – A fusion performed on the back surface of the spine.

Rib hump – The prominence formed by ribs on the curve, caused by rotation of the spine and attached ribs.
Risser sign – The radiographic appearance of the iliac growth plate used to predict growth.

Scoliosis – Sideways curvature of the spine greater than 10 degrees.

Skeletal maturity – When the bones, including the spine, are finished growing, skeletal maturity has been reached.

Spinal column – The spinal column is made up of individual vertebral bones, ligaments, and discs. It surrounds the spinal cord.

Spinal cord – A group of nerves, which carry and receive signals to and from the brain, arms, legs, and many internal organs. The spinal cord goes through the spinal column.

TLSO – Thoraco-lumbar-sacral orthosis. A brace or spinal orthosis which extends from the chest to the pelvis.

Vertebra – Individual bones which make up the spinal column.

Vertebral body – The front portion of the individual vertebra.