Dear patient and family,

This handbook is written to help you learn more about your child’s spine surgery. We ask that you bring this handbook to the hospital and all doctor appointments. Visit choa.org/medical-services/orthopaedics/scoliosis-and-spine-program/scoliosis/spine-surgery to learn how to get ready for spine surgery. Watch the video and review the spine surgery handbook.

We hope that the information will help you understand what happens before, during and after your child’s surgery. We will guide you through the steps you will be taking on the path to recovery. You can find words in *italics* in the Glossary on Page 62.

This guide should not replace instructions given to you by your child’s doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about this subject. Your child’s doctor is the best source of information about what is best for your child’s treatment and care.

Call 911 or go to the nearest emergency department right away in case of an urgent concern or emergency.

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Welcome

Thank you for choosing the Children’s Healthcare of Atlanta Orthopaedics Program. Our goal is to:

- Provide your child with quality care.
- Support you and your family during your child’s care.
- Teach you about your child’s *scoliosis* and treatment plan.

According to *U.S. News and World Report*, Children’s ranks among the top pediatric orthopaedic programs in the country. We offer care for babies, children and teens with:

- Bone, joint and muscle problems (*orthopaedic*)
- Nervous system problems that affect the muscles, bones and joints (*neuromuscular*)
- Problems that occur after accidents and injuries (trauma)
- Musculoskeletal tumors

We also offer these services:

- Physical (PT) and occupational therapy (OT)
- Braces and artificial limbs (orthotic and prosthetic devices)

Our program consists of many team members who all work together with a surgeon to help your child. This includes anesthesiologists, infectious disease specialists, critical care specialists, rehab specialists and others who provide specialized care such as:

- Physical and occupational therapists
- Orthotists and prosthetists
- Certified athletic trainers
- Child life specialists
- Nurses

Satisfaction Survey

We are always trying to improve care and need your feedback. While you are at home, you will receive a satisfaction survey from Children's. Please complete the survey as soon as possible. We value your thoughts on your family's experience at Children's.

Important Phone Numbers

Egleston and Scottish Rite hospitals (main hospital number): 404-785-KIDS (5437)

Spine program manager: 404-785-7575

Visit choa.org/medical-services/orthopaedics for more information about the Children's Orthopaedics Program.

Orthopaedic surgeon (spine doctor): __________________________

Pediatrician or family doctor: _______________________________

Drug store or pharmacy: ___________________________________

Emergency phone numbers

Call 911 in case of an urgent concern or emergency.

Your nearest emergency department is ________________________

Orthopaedic Team

Our healthcare team is here for you and your family. We work together with you to provide your child with quality care. You will meet many doctors and staff during your child's stay with us. Some of them are included in the list below.

Orthopaedic spine surgeon: A pediatric orthopaedic surgeon who has developed an expertise in the evaluation, medical and surgical management of pediatric, adolescent and young adult spinal conditions. The orthopaedic spine surgeon is in charge of the team caring for your child before, during and after surgery.

Pediatric orthopaedic resident: A surgeon completing subspecialty training in orthopaedic surgery. They have graduated from medical school, completed a surgical internship and are completing the pediatric orthopaedic subspecialty portion of orthopaedic specialty training to prepare for a career in orthopaedic surgery.

Pediatric orthopaedic fellow: An orthopaedic surgeon who is completing training in the field of pediatric orthopaedic surgery – a subspecialty of orthopaedic surgery. They have graduated from medical school and have completed a surgical internship and orthopaedic residency training. They are completing pediatric orthopaedic subspecialty training to prepare for a career in pediatric orthopaedic surgery.

Pediatric anesthesiologist: A doctor who is specially trained to give children and teens *anesthesia*. Anesthesia is the medicine that causes a deep sleep during surgery. This doctor also monitors your child during the surgery.

Physiatrist: A doctor who is specially trained in physical medicine and rehab. If your child needs to stay in the hospital for therapy, this doctor will oversee your child's medical care and therapy.

Nurse: A registered nurse (R.N.) has special training to provide care for your child before and after surgery.

Physician assistant or nurse practitioner: Staff with advanced medical training who work closely with the surgeon to help manage your child's care.

Registered dietician: A team member who checks your child's food intake and overall growth. They can offer ways to help your child gain or lose weight if needed. They may also be called clinical nutritionists.

Child life specialist: Staff with special training to help your child and family cope with the stress of being in the hospital. A child life specialist can give you and your child a tour of the hospital, teach your child about surgery, and offer ways to cope with fear or pain.

Social worker: A person trained to provide your family with guidance and counseling. Social workers can help with feelings of normal grief and coping skills while your child is in the hospital. They can also help you with resources you may need such as lodging, transportation, finances and support groups.

Physical therapist (PT): A team member who checks your child's motor skills. Physical therapists plan and do therapy to help your child gain or regain strength and ability to move.

Occupational therapist (OT): A team member who can help your child be more independent in caring for themselves after surgery. This can include dressing, brushing their teeth and brushing their hair.

Orthotist: A team member who designs, builds and fits braces to support body parts. This includes the neck, back, arms and legs.

Prosthetist: A team member who designs, builds and fits artificial limbs.

Chaplain: A team member who provides spiritual support to your child and family. Chaplains also lead interfaith worship services in the hospital chapel.

Case manager: A registered nurse who helps to plan and coordinate your care needs for when you go home. This nurse also provides resources about insurance and payment issues.

Inpatient Care Team

Ask your hospital care team to print their names and phone numbers on the list below. Keep the chart nearby while you are in the hospital.

Orthopaedic surgeon (spine doctor): ___________________________

Nurse: ____

Physical therapist: ____

Occupational therapist: _______________________________________

Child life specialist: ____

Case manager: ____

Other: ____

Patient Safety

Our goal at Children's is to provide the safest possible care for all of our patients. You are our partner in this process.

What should I do if I have a question about my child's care?

- We know that you and your child are going through many new things. If you have a concern or question about anything, please speak up and ask a staff member.
- If you do not understand, please speak up and ask questions. This includes if you do not understand a consent form or any other part of your child's care.
- It is your right to have things explained to you in a way that you can understand.
- If you think your child is not acting normally or you have other concerns about how your child looks or feels, please speak up and tell us.

How can I help keep my child safe in the hospital?

To help keep your child safe, please do these 6 things regularly:

1. **Wash your hands** well with soap and water for at least 20 seconds or use alcohol-based gel or foam. Wash your child's hands as well when needed.
2. Everyone who comes to see your child should wash their hands or use alcohol-based gel or foam, including hospital staff. Please speak up if we do not do this.
3. Keep the identification (ID) band on your child. Let your caregiver know right away if it comes off.
4. Hospital staff should check your child's ID band when giving medicines, collecting specimens and labs, or doing procedures. Please speak up if we do not do this.
5. To help prevent falls, keep your child's bed or crib side rails up and the bed in its lowest position.
6. Please speak up. Ask a staff member whenever you have questions or concerns. Be involved in making decisions about your child's care. Write down important facts and questions so you can remember them later.

Why does my child need an ID band while in the hospital?

All patients in the hospital must wear an ID band. This helps keep your child safe by letting our staff know they are treating the correct patient. Even if the hospital staff knows your child, they should read the ID band.

- Keep your child's ID band on. Let the staff know right away if it comes off.
- Our staff will actively involve you when we ID your child. We will ask you to verify your child's name and date of birth, and we will check your child's ID band before: giving medicines and blood products, collecting specimens and labs, and doing treatments or procedures. At night when you and your child are sleeping, we will check the ID band ourselves.
- If someone does not check the ID band first, please speak up and ask them to do so.
- Children with allergies also wear a separate red band.
- If your child is allergic to latex, they will have a separate green band.
- If your child falls often, they will have a separate yellow band.

Why do we need to use bed side rails in the hospital?

- When a child is sick and takes certain medicines or undergoes certain procedures, their chances of falling are increased.
- If a child gets hurt, their hospital stay can be longer than it should be. This may add to the stress of your child's recovery.

To keep your child safe:

  - Keep the bed side rails up and make sure they lock.
  - If you do not know how the bed side rails work, please speak up and ask a staff member.

If one of my child's monitors beeps, what should I do?

Most medical equipment has an alarm, which helps us keep your child safe.

- When the alarm sounds, it lets the nurse know something needs to be checked.
- If someone does not come right away, please leave the alarm on and push the nurse call button or get a nurse. Please do not turn off alarms.

Other safety tips

Prevent falls

- Always let your child's nurse or caregiver know if you are leaving the room. Do not leave your child alone.
- Keep the bed at its lowest position to the ground.
- Make sure your child always sleeps in the bed. Do not allow your child to sleep on the couch or in the chair.
- Have your child wear shoes or non-skid socks each time they get out of bed. If you do not have any, please speak up and ask our staff for a pair.
- Do not allow your child to:
  - Play with any medical equipment, such as monitors.
  - Ride on I.V. poles.
  - Run in the hallway.
  - Climb on furniture.

Medicine safety

- Tell the doctors and nurses about any allergies or drug reactions your child may have.
- Keep a complete and current list of the medicines your child is taking. This includes prescriptions, over-the-counter medicines, herbs and supplements.
- Share this list with each of your child's doctors.
- Be sure you know the name of your child's medicine. Also know:
  - Why it is used
  - When and how to give it
  - Any side effects
  - Any other medicines, foods or drinks to avoid when taking it
- Ask your child's nurse or doctor about any medicines that are different than normal. This includes how they look and when the nurse gives them to your child.

Know test results

- Know the results of your child’s tests. Do not presume tests are OK if you do not hear from your doctor.
- Please speak up. Ask for the test results and ask someone to explain them to you.

Preventing infection

Preventing infection starts at home—before your child’s surgery. Be sure that your child wears clean clothes and uses clean sheets and towels before and after surgery.

Why is hand hygiene important?

We all carry germs everywhere we go. Good hand hygiene is one of the most important things that you and your family can do to stay healthy. Teach your family good hand hygiene. Insist that babysitters and childcare workers do the same.

Good hand hygiene helps prevent the spread of germs

- Hands can carry germs that cause colds, pinkeye, diarrhea and sometimes even serious illnesses.
- You and your child come in contact with germs each day when you touch things like doorknobs, toys, books, phones and grocery carts.
- Germs can enter your bodies when you touch unclean hands to your nose, mouth, eyes or an open cut or sore.

Five simple steps for washing yours and your child’s hands:

1. **Wet**—use warm running water. Using warm water is a comfort measure, but it does not kill germs.
2. **Lather**—use soap until you get lots of bubbles. If your child’s doctor tells you to use only antibacterial soap, check the bottle and make sure it is labeled that way.
3. **Wash**—rub hands together, washing the entire hand for at least 20 seconds. This includes all of the fingers, both thumbs, between and under fingernails, back of hands, palms and wrists. Slowly singing one verse of “Happy Birthday to You” is about 20 seconds.
4. **Rinse**—rinse hands well under running water. Rub your hands together as you rinse to remove all the soap, dirt and germs.
5. **Dry**—dry with a paper towel instead of rubbing with a cloth towel. In the hospital and public restrooms, use a dry paper towel to turn off the faucet.

Use an alcohol-based gel or foam when you cannot wash your hands. Alcohol-based gels and foams kill germs on your hands, but they do not remove dirt or grime.

You still need to wash hands to get them clean if you:

- See dirt or grime on your hands.
- Handle uncooked meats.
- Change diapers.

Never use an alcohol-based gel or foam before you:

- Prepare food.
- Touch your or your child’s eyes or mouth.
- Put in or take out contacts.

Clean your hands before you:

- Prepare food.
- Eat, drink or feed your child.
- Treat a cut or scrape.
- Care for someone who is sick.
- Give medicines.

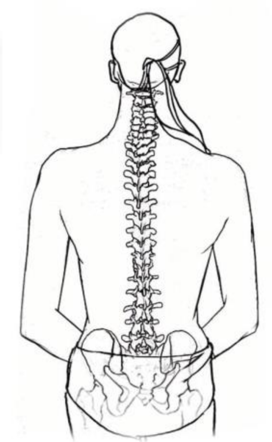
Clean your hands after you:

- Go to the bathroom.
- Help your child use the bathroom or change a diaper.
- Handle uncooked food.
- Touch garbage or anything that might have germs.
- Blow your nose, cough or sneeze.
- Wipe your child's nose.
- Care for someone who is sick.
- Play with or touch pets.
- Come from any kind of public place.

In the hospital, always wash your hands before you enter and before you leave your child's room. Also wash your hands before handling your child's lines or tubes.

Notes

Spinal Deformity



Normal spine

What is scoliosis?

Adolescent Idiopathic Scoliosis (AIS) is a sideways curve of the spine. Adolescent means children over the age of 10 and teenagers. *Idiopathic* means that we do not know what causes it.

The curve can make your child's spine look more like an "S" or a "C" rather than a straight line.

What is kyphosis?

Kyphosis is a forward curving of the spine that causes a bowing or rounding of the back.

Causes of idiopathic scoliosis and kyphosis

Both tend to run in families, but there is no known cause. Things that do not cause scoliosis or kyphosis include:

- Bad posture
- Heavy backpacks
- Poor diet

Spinal curvature

Signs of scoliosis and kyphosis

Your child may have 1 or more of these signs:

When standing up:

- One shoulder blade sticking out more than the other
- Uneven shoulders
- Uneven hips

When bending forward:

- A rib hump, called a rib prominence
- A lower back hump, called a lumbar prominence

Scoliosis and kyphosis do not usually cause back pain. If your child feels back pain, tell the doctor.

Medical tests to screen for scoliosis and kyphosis

Two common tests include:

- Scoliosis and kyphosis screening exam – this is done by a trained expert like a nurse, doctor or physician assistant. They are looking for signs of scoliosis or kyphosis.
- *X-rays* of the back and spine that can:
  - Show the doctor if your child has a curve in his spine.
  - Measure the amount of curve in your child's back. The curve is measured in degrees.
  - Diagnose the type of scoliosis.
  - Tell the doctor approximately how much growing your child has left to do. Once the doctor knows this, they will be able to tell if the curve will get worse or not. If your child is still growing, the doctor may want to check the curve until they finish growing.

Treatment of scoliosis and kyphosis

A bone and muscle doctor called an orthopaedic surgeon usually treats scoliosis and kyphosis. Treatment depends on the degree of your child's curve and how much growing they have left to do. Sometimes, no treatment is needed.

If your child needs treatment, the doctor will talk with you about specific care for your child. Some guidelines may include these 3 options:

- Observation—checking for changes in the curve with an X-ray 2 or 3 times a year.
- Bracing—wearing a form-fitting brace each day for a certain number of hours.
- Surgery—surgically manipulating the bones in the spine to keep the curve from getting worse and decrease deformity.

Different kinds of surgery are tailored to each child's specific *pathology*.

- Growth modulation surgery uses the spine's growth to improve the deformity.
- Curve modulation surgery is a sequence of procedures that decreases spinal deformity but allows spinal growth.
- Spinal fusion is a standard procedure that decreases spinal deformity and halts curve progression and growth in the fused segments.

Spine surgery

Orthopaedic surgeons offer many options to meet the needs of children and teens with different spine conditions. When surgery is needed, your child's doctor will talk with you about the best surgical choice for your child. This could include:

- Spinal fusion
- Growing rods
- VEPTR

What is a spinal fusion?

A spinal fusion is surgery that joins or fuses some of the bones of the spine. These backbones are called *vertebra*. Fusing the bones helps to prevent the curve from getting worse. It may not completely correct the curve.

In general, there are 3 ways to do spinal fusions.

1. Anterior—done on the front part of the spine through an *incision* in your child's side.
2. Posterior—done on the back of the spine through an incision in your child's back. This is the most common.
3. Anterior-Posterior—done on the front and back part of the spine through 2 incisions.

The time it takes your child to recover depends on:

- Their general health and overall medical condition
- The amount of curve in your child's back
- The type of spinal curve your child has and how flexible the curve is

All 3 fusion approaches use pieces of bone, metal rods, screws and hooks to fuse the backbones together.

- The metal rods and screws help to keep the bones in the right place and hold them straight.
- The *bone graft* acts as a biologic bridge and grows into the spaces between the backbones. This fuses them together.

The bone graft can come from either:

- A piece of bone from your child’s own hip area. This is called an *autograft*.
  - Your child will have another incision over their hip area.
  - It should not affect your child being able to walk or run.
- A bone bank from someone who donated their bone—this is called an *allograft*.
- Your surgeon will talk with you about the best choice for your child.

Growing rod and VEPTR surgical procedures use specialized expandable instrumentation to temporarily help with curve correction and control progression without fusion. Both of these procedures allow the surgeon to lengthen the instrumentation constructs to accommodate spinal growth.

What are growing rods and VEPTRS?

Growing rods allow for continued, controlled growth of the spine. Metal rods are attached to the spine and lengthened during a simple outpatient procedure. This is done through the back of the spine.

- The child returns about every 6 months to have the rods “lengthened” approximately 1 centimeter to keep up with the child’s growth.
- Some children will have to wear a brace to protect the instrumentation.
- When the child becomes older and the spine has grown, the doctor will remove the instrumentation and perform a formal spinal fusion surgery.

Vertical expandable prosthetic titanium rib (VEPTR) surgery can help children who have scoliosis and other spine conditions, such as thoracic insufficiency syndrome. This condition causes severe deformities of the chest, spine and ribs. Almost all children with this condition also have scoliosis or other spinal problems.

To correct these problems, the surgery involves placing a curved metal rod along the child’s ribs, near the spine. This helps keep the spine straight and expands the ribs to allow the lungs to grow.

There is no set age for the surgery, but it is recommended between the ages of 18 months and 5 years.

After the surgery:

- Your child will stay in the hospital for a few days after the VEPTR insertion.
- Every 4 to 6 months, the metal rod will be expanded. This happens until your child’s skeleton stops growing. Expanding the rod helps the thorax grow. This is the area of the body that houses the lungs, heart and other body parts.
- Your child may be fitted for a brace to wear after surgery.
- Your child will be able to take part in physical activity in about 1 month.

What is a Magnetic Expansion Control (MAGEC rod)?

MAGEC rods are a type of expandable implantable rod that do not require multiple surgeries for lengthening. A small magnetic motor is incorporated into the rod. The doctor has a magnetic device that can activate the motor through the skin and control the lengthening. This will require visits to the doctor’s office every 6 weeks to 3 months. It does not require surgery or anesthesia as the MAGEC lengthening is painless. Not all children are MAGEC candidates as only limited sizes are available and children have to be thin enough for the magnet to activate the device.

Notes

Preparing for Spine Surgery

Preparing for spine surgery

You can help prepare your child or teen for surgery. Preparing ahead of time can help:

- Calm your child’s fears.
- Make getting better easier and faster.
- Calm you as you focus on them, what to expect and how to care for them afterwards.

Like all people, children and teens are sometimes scared of certain things. Below are some common fears your child may have about surgery:

- Being away from school and friends
- Their body image, including what they look like before and after surgery.
- What others will think about them being sick or in the hospital
- Loss of control and independence
- Not having privacy
- Needles and shots
- How surgery might affect what they can do in the future
- Pain
- Surgery and its risks
- Waking up during surgery or not waking up after surgery
- Dying

Talk with your child

This list of tips below can help you when you talk with your child about surgery.

- As soon you and your child decide to have surgery, sit down with your family and make a plan.
- Allow your child to have as much control as possible. Give them choices when possible.
- Have your child make a list of questions to ask the medical team.
- Talk about fears and be honest. Children need truthful information to build trust.
- Let your child know that many other people have had the same type of surgery.
- Plan for distraction tools, visits from friends and comfortable PJ’s.
- Offer praise, positive comments and support.
- Talk with your child and the medical team often. This helps everyone stay in touch and feel more at ease.
- Let your child know it is OK to be scared and cry. They may need to know you have the same worries they do. Let them know you are there to support them.
- Let your child know that you will be waiting close by during the surgery and will see them as soon as they get back to the room.

Take care of yourself

- Make sure you know about your child’s surgery and know what to expect. This can help decrease your fears about it.
- Make sure you, your child and your family are well rested.
- Take care of yourself. Your child can sense and react to your stress level.

What to do before surgery

Follow the doctor’s advice to help get your child ready for surgery. They may need:

- A pre-op (before surgery) visit to meet with members of the medical team which include:
  - A member of the anesthesia team who will ask lots of questions about your child’s medical history.
  - A child life specialist who will walk your child through the steps of surgery and give a tour of the area.
- Blood tests
- CT scan or MRI
- X-rays
- A pre-op visit with the doctor or with a nutritionist to talk about nutrition concerns. This could include being overweight or underweight, recent weight loss or weight gain, and poor eating habits.
- You can find a pre-op checklist in the Resources section of this handbook on page 47.

Note to parents: If your child gets tube feedings, talk with the doctor or nutritionist to review feeding schedule is adequate to prepare your child for surgery.

1 month before surgery

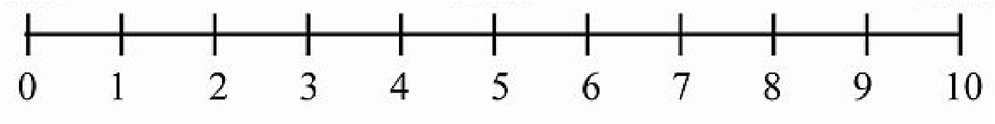
- Your child should eat foods with lots of fiber, iron and protein for 1 month before surgery. This includes foods like meats, nuts, eggs and green, leafy vegetables.
- Check with the doctor to see if your child needs a multivitamin with iron.

Days before surgery

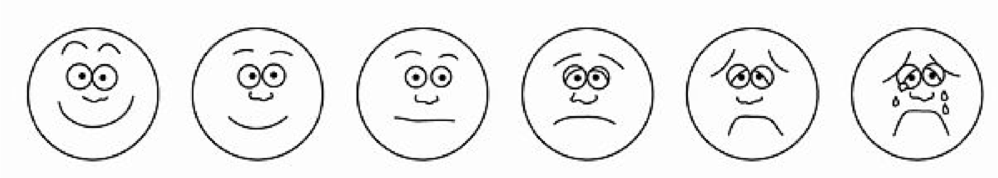
- Your child’s doctor may suggest taking an over-the-counter laxative like Miralax for 2 or 3 days before surgery. This can help to prevent constipation (hard bowel movements) after surgery.
- Your child should drink lots of fluids a few days before surgery, so their body is well hydrated. This will also help prevent constipation.
- Pack your child’s things. Be sure to include a robe or loose fitting shorts and t-shirts. Your child may also like to bring a phone, charger, books or DVDs. You will find a ‘What to Bring’ handout in the Resources section of this handbook on page 48.
- If your child has long hair, wash and put it up in a metal-free ponytail holder.
- Your child should bathe or take a shower the night before surgery.
  - They should pay close attention to areas like under the arms and groin area.
  - The night before surgery, your child’s skin should be washed with the CHG wipes the nurse gave you at the pre-op clinic. Use them just like the nurse taught you.
- Read the ‘Cleaning with CHG cloths’ handout in the Resources section on page 54.
- Your child should not take a shower or eat the morning of surgery.
- Your child should not wear contacts, makeup, jewelry or nail polish to the hospital on the day of surgery.

Familiarize your child with the pain scale they will be using after surgery.

- If 10 is the worst pain you have ever felt and zero is no pain, what number best describes your pain right now?



- If the sad face is the worst pain you have ever felt and the happy face is no pain, which face seems the most like your pain right now?



Notes

After Surgery: In the Hospital

Your child's plan for recovery
Idiopathic spinal fusion
Recovery for: ___________________________________

Your child will be able to go home when they are able to:

- Eat a regular diet.
- Control pain with medicines they swallow.
- Walk without help.
- Tell the nurse or therapist what things they can and cannot do at home.

Most children are discharged home 2 to 3 days after surgery.

We invite you to learn more about your child's care for a spinal fusion. This Plan for Recovery can give you general information about what to expect during your child's hospital stay. The exact course and treatment will be based on your child's needs. If you have questions or concerns about your child's care, ask your child's doctor or our staff questions at any time.

The day of the surgery

When your child arrives at the hospital, our nurses will:

- Check your child's vital signs (blood pressure, pulse, breathing rate and temperature).
- Use the CHG cloths to wash the back.
- Take your child to the operating room for surgery.

Developed through the efforts of Children's Healthcare of Atlanta and physicians on Children's medical staff in the interest of advancing pediatric healthcare. This is a general guideline and does not represent a professional care standard governing providers' obligation to patients. Ultimately the patient's physician must determine the most appropriate care.

Confidential privileged quality peer review material pursuant to GPR statute Georgia Code Sections 31-7-130 to 133, the HCQI Act of 1986 and the Patient Safety and Quality Improvement Act of 2005. This product shall not be duplicated or distributed without written permission from Patient Safety or Risk Management.

Your child's plan for recovery

Idiopathic spinal fusion

Recovery for: ___________________________________

Right after surgery	
Diet	• May be allowed ice chips and clear liquids as tolerated
Activity	• Use the incentive spirometer about 10 times an hour while awake to help keep the lungs clear • Make a log-roll turn about every 2 hours around the clock with help from staff
Medicines	• Through the intravenous (I.V.) line: – Fluids – Antibiotics for about 24 hours to help prevent infections – Pain medicine with a patient-controlled analgesia (PCA) pump – Medicine for an upset stomach if needed
Pain management Pain management goals for day of surgery: Rest Sleep Participate in turning in bed Deep breathing	**Pain management plan today:** • Valium through the I.V. line for tight muscles (spasticity) as needed • Pain medicine with a patient-controlled analgesia (PCA) pump • I.V. pain medicine if the PCA pump does not control pain well enough • Position for comfort • Support relaxation techniques **Child or teen's plan:** • Tell your nurse if your pain is not relieved or you have muscle spasms • Tell your nurse if you are itchy • Tell your nurse if your stomach is upset or hurts • Use your PCA as directed • Use your relaxations skills to help relax • Use the comfort measures you learned about such as pillow positioning and music
Other care	• Check vital signs, circulation and movement regularly **around the clock** • **Tell your nurse if your child has:** – Numbness or tingling in the arms or legs – Decreased feeling in the arms or legs – Dressing soaked with blood • Hemovac drain to collect fluid from wound if present • Oxygen as needed • Pulse oximeter to check blood oxygen level • Catheter to drain urine

Most patients go home on day 2 after surgery, but some may stay more or less days depending upon how they are doing. This is not reflective of whether the surgery was a success or failure.

Day after surgery (post operative day 1)	
Diet	• Clear liquids to regular diet, depending on what your child can eat
Activity	• Use the incentive spirometer often to keep the lungs clear • Will be seen by physical therapist (PT) • Make a log-roll turn about every 2 hours with help from staff • Move from bed to chair several times with help from staff • Begin walking with staff and family • You may help your child with moving around
Medicines	• Through the I.V. line: – Fluids—may be stopped if able to take liquids by mouth without an upset stomach – Medicine for an upset stomach if needed – Medicine for constipation if needed
Pain management Pain management goals for day after surgery: Get out of bed at least of 3 times Take part in physical therapy Take part in occupational therapy Turning in bed Deep breathing Rest and sleep	**Pain management plan today:** • Stop PCA pump • Begin pain medicine by mouth every 4 hours around the clock • Begin an anti-inflammatory medicine • Valium for tight muscles as needed • I.V. pain medicine if needed for more severe pain • Time PT visits with pain medicine • Help with getting child or teen out of bed • Position for comfort • Support relaxation techniques **Child or teen’s plan:** • Tell your nurse if your pain is not relieved or you have muscle spasms • Tell your nurse if your stomach is upset or hurts • Move in bed often using a logroll • Get out of bed with help • Rest between therapy visits • Use your relaxation skills to help relax • Use the comfort measures you learned about such as pillow positioning and music
Other care	• Check circulation and movement regularly **around the clock** • **Tell your nurse if your child has:** – Numbness or tingling in the arms or legs – Decreased feeling in the arms or legs • Pulse oximeter to check blood oxygen level if PCA pump is still being used • Foley catheter may come out • Blood tests if needed • Fever is common in the first day or two – your child may get acetaminophen • Continue to help your child move **NOTE:** Teen girls may start their period after the surgery

Your child’s plan for recovery

Idiopathic spinal fusion

Recovery for: ___________________________________

Post-operative day 2 and 3, or day of discharge	
Diet	- Regular
Activity	- Walk at least 3 times a day around unit and begin stair training - Get out of bed with assist of <u>family</u>
Medicines	- Stop I.V. fluids but I.V. remains - Pain medicines by mouth - Medicine for constipation
Pain management Pain management goals for post operative day 2 and 3, or day of discharge: Get out of bed at least of 3 times and walk often Take part in your bath and ADL’s Take part in physical therapy including stairs Take part in occupational therapy Continue turning in bed Deep breathing Rest and sleep	**Pain management plan today:** - Valium by mouth for muscle tightness as needed - Pain medicine by mouth every 4 hours as needed - I.V. pain medicine if needed for more severe pain - Continue anti-inflammatory medicine - Assist with walking and moving - Position for comfort - Support relaxation techniques **Child or teen’s plan: While pain medicines are not scheduled on a regular basis, be sure to ask for them before pain becomes severe** - Ask for pain medicine before an activity or if you begin to hurt - Tell your nurse if your pain is not relieved or if you have muscle spasms - Tell your nurse if your stomach is upset or hurts - Get out of bed with help - Walk and move with help - Move in bed often using a logroll - Rest between therapy visits - Use your relaxation skills to help relax - Use the comfort measures you learned about such as pillow positioning and music
Other care	- Check circulation and movement regularly - **Tell your nurse if your child has:** – Numbness or tingling in the arms or legs – Decreased feeling in the arms or legs - Hemovac drain removed, if not already done - Remove Foley catheter, if not already done - Chest and back X-rays - Continue to help your child with moving and sponge bathing

Notes

After surgery: In the hospital

Your child will go to the PACU (post anesthesia care unit or recovery room). When they are ready, our staff will move them to a patient care area. Your child may look a little pale and have a puffy face for 1 or 2 days. This is normal and is due to the way your child was positioned during surgery. If the doctor thinks your child needs special care overnight, they will go to the intensive care unit (ICU). Our staff will check on them often through the night.

The next few sections will also be covered with a child life specialist during your child's pre-op visit.

Monitors and checks

- Your child may need oxygen to help them breathe easier as they wake up. If so, a plastic face shield will blow an oxygen mist into your child's face. A machine called a pulse oximeter will check their oxygen level. A wire connects the machine to a bandage on your child's finger and does not hurt.
- A machine called a cardiac monitor will check your child's heart rate and breathing rate. Thin wires connect the monitor to 3 electrodes on your child's chest. These electrodes feel like stickers and will not hurt.
- Our staff will check your child's temperature, heart rate, blood pressure and breathing rate often, even at night.
- Our staff will also check the feeling and movement of your child's legs and feet often, even during the night. This is to help make sure the nerves and blood vessels in their legs are working well. Be sure to tell the doctor or nurse about any changes in the way your child says their legs or feet feel.

I.V.'s, drains and tubes

Your child will have 1 or 2 *I.V.'s*. I.V. stands for intravenous (in your vein). They will get an antibiotic (a germ-killing medicine) through the I.V. Your child will also get fluids through the I.V. until they can eat and drink.

- Once your child can drink well, the I.V. may be turned off.
- The I.V. will remain in place until they are ready to go home.

A small, soft tube called a *Foley catheter* will drain urine from the bladder. A nurse puts it in place during surgery while your child is sleeping. The tube goes into the same opening through which they urinate.

- A bag connected to the tube collects urine. Our staff will empty the bag 2 or 3 times a day. This helps the nurse and doctor keep track of your child's body fluid level.
- The Foley is removed on the morning after surgery. After they remove the tube, the nurse or patient care tech will help your child get up to the bathroom.

Your child may have a small tube coming out through the skin near the wound. This is called a Hemovac and is used to drain extra fluid from the wound into a small sterile container. The tube is removed at the bedside 1 or 2 days after surgery and should not hurt.

Pain management

Pain management is a vital part of your child's stay. At Children's, we work as a team with your child to decrease pain when possible. You know your child best. Please tell us when your child is in pain or if there is anything else we can do to help decrease your child's pain.

- Our staff will check your child's pain often using a pain scale.
- The pain scale contains a pain rating from 0 to 10 (0 is no pain, 10 is the worst possible pain). Our goal is to lessen the pain as much as possible.

See the Discomfort After Surgery section of this handbook on page 39 for more information.

What is a *patient controlled analgesia (PCA) pump*?

Pain after surgery can make it hard to take a deep breath, move and walk. Managing your child's pain will make it easier for them to take part in their care and recovery. One of the ways to manage pain is to use a PCA pump.

The PCA pump is a small, battery-operated machine that delivers pain medicine (analgesia) to your child. The pump controls a syringe that contains the pain medicine ordered by your child's doctor.

How does it work?

- Your child can push a button on the pump when they have pain. The pump then delivers the pain medicine to them.
- They can also use it before an activity that might cause pain.
- The medicine goes into your child's vein through their I.V. and into the bloodstream when they push the button.
- A PCA pump enables your child to decide when to take pain medicine. They are the only person who should press the button unless the doctor orders otherwise.
- The pump is set so your child cannot take too much medicine or use the pump too often, even if they push the button.
- Your child's doctor can tell how much pain medicine your child needs to stay comfortable. The doctor will also make changes when needed.

Why should my child use a PCA pump?

- When a child has pain, they may be scared to ask for pain medicine. Some children feel that a pain "shot" is worse than the pain itself.
- A PCA pump is already connected to an I.V., so an extra "shot" is not needed. The pump works well for children because they are not scared to say they have pain.
- Please let your child's nurse know right away if you think your child's pain is not being well controlled.

How safe is the PCA pump?

- The pump has a computer in it that is set to prevent too much medicine from being delivered.
- It also has a "lockout" period that prevents your child from getting a dose of medicine too soon, even if they push the button.
- The nurse and other care team members watch your child closely for signs of sleepiness (too much pain medicine) or pain (not enough medicine).

When should I call the nurse?

Pain medicine can cause stomach upset and constipation. Please let your child's nurse know if you notice side effects from the pain medicine such as:

- Warm, flushed face
- Feeling too sleepy or groggy or is hard to wake up
- Feeling grouchy
- Nausea or vomiting (throwing up)
- Skin rash or itching and scratching
- Trouble breathing

Also tell your child's nurse **right away** if you think your child's pain is not well controlled.

If your child does not have a PCA pump, their nurse can give them pain medicine through the I.V. Once your child is cleared by the doctor to eat and drink, the nurse will turn off the PCA pump. Your child can then take their pain medicine as a liquid or pill by mouth.

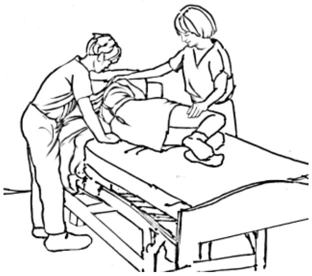
Other things your child can do to help their pain include:

- Tell us what has helped in the past.
- Breathe deeply and slowly.
- Watch videos or TV.
- Listen to music.
- Imagine they are in their favorite place.
- Ask their nurse to call the child life specialist for more tips to help decrease their pain.

Moving after a spinal fusion

- *Physical therapy* will begin the morning after surgery. A physical therapist will teach you and your child the safe way for them to move.
- Your child can give themselves a dose of pain medicine from the PCA pump before or after their therapy session to help decrease any pain.
- Moving and turning in the right way can help your child heal better, get stronger and have less pain.
- It is very important that your child changes positions often, even at night. This helps keep their lungs clear and prevents soreness and skin problems. Your child will be sore after surgery, but the nurse and you can help them. As your child begins to feel better, they will be able to change positions themselves.

Turning in bed



When turning, your child should keep their body and back in a straight line like a log. A physical therapist and nursing will help them and teach them how to roll in one continuous motion. This is called a logroll. As your child starts feeling better, they can help turn themselves. Your child should:

- Roll so their hips, knees and shoulders stay in line and move together. Do this anytime they change positions in bed.
- Avoid any twisting and bending motions.
- When lying on their side, place pillows between the knees and behind their back to help them feel better. They can also place a pillow under their top arm.
- When lying on their back, place pillows under their knees and arms.

How to sit on the side of the bed

A physical therapist will teach your child the proper way to sit up. They can also follow these steps to help sit up on the side of the bed:

- Keep their back straight.
- Bring their knees up so their feet are on the bed.
- Log roll onto their side.
- Push up to sitting by pushing against the mattress with their elbow and their hand.
- Push up with their arms at the same time they lower their feet.

How to get out of bed

A physical therapist will help your child get out of bed and walk the first morning after surgery. The therapist and nurse may also have them sit in a chair for at least 45 or 60 minutes 3 times each day, starting the morning after surgery. A physical therapist, nurse and you can help your child get out of bed and walk at least 3 times each day while they are in the hospital.

Helpful hints for your child with daily activities

- Sit in a chair for at least 45 to 60 minutes. Do this at least 3 times starting the day after surgery.
- Walk in the hallways at least 3 times each day with help.
- The sooner they begin moving, the faster they will get better. It is never easy to get up the first time after surgery, but it will help decrease their risk of problems.
- Each day, move around more than they did the day before.
- As they progress, the physical therapist will teach you and other family members how to help with mobility and exercises. If your child has stairs at home, the physical therapist will help them practice going up and down stairs.

Care of the lungs

Our staff will give your child a small device called an *incentive spirometer* after surgery.

- The nurse or respiratory therapist will teach your child how to use it to do breathing exercises. This will help prevent pneumonia and other lung problems. Hugging a pillow while they cough puts less strain on your child’s back and can help decrease pain.
- Many children have a slight fever after surgery. Using an incentive spirometer often can help your child’s temperature return to normal.

Feelings

Your child may go through many mood swings while in the hospital. They may become withdrawn and not want to talk or answer questions. There are times when they may need to be alone. All of these are very normal feelings.

Some tips to help your child deal with their feelings:

- Stay connected with friends.
- Make time for visits, phone calls, Facebook, Twitter and other social media.
- Each day, they can remind themselves of what they did that they could not do the day before. They can stay positive and aware of their progress.

Some tips for parents include:

- Be patient and understand their child may not feel like themselves.
- Ask friends to send cards or letters during the hospital stay or healing time at home.

As your child's activity level increases and they begin feeling better, their feelings and mood will improve. Once they can sit in the chair and walk to the bathroom, they may feel better if they take a sponge bath, brush their hair or put on makeup.

Many times, teenage girl's menstrual periods will be irregular after surgery. This is very common. Your child's period should return to normal in 1 or 2 months.

Eating and drinking

Right after surgery, your child may only be allowed to have a small amount of ice chips or sips of clear liquids. After this, the doctor will increase their diet until they are able to eat and drink like normal. If they like to chew gum, pack some in your suitcase. **Chewing gum** after surgery may help their bowel function return to normal more quickly.

If your child has nausea (a queasy, sick feeling), let the nurse know. They can give your child medicine to help them feel better.

Once your child is able to drink clear fluids and eat small amounts of food, they can begin to swallow pain medicine.

Constipation, or trouble having a bowel movement (BM), often occurs due to the effects of the pain medicine and being less active. To help prevent this, have your child drink plenty of fluids and begin moving around as much as they can.

If your child has problems eating or drinking, tell the nurse. They nurse can call a nutritionist to talk with you and your child. Your child needs to be able to take in enough fluids, protein and vitamins to heal well.

Note to parents: If your child received tube feedings before surgery, it is best to restart them as quickly as possible. The feedings may not be the same as you used at home, as your child may need increased calories and protein for healing.

Preparing to go home after spinal fusion surgery

Occupational therapy (OT) can help your child be more independent when caring for themselves after surgery. The occupational therapist can help your child:

- Learn how to bathe, dress, groom and toilet themselves better and easier. The therapist calls these things ADLs or activities of daily living.
- Try new ways of doing things that can help keep them and their back safe.
- Your therapists will see them after surgery on day 2. They will have your child practice ADLs.

Some OT tips to help your child are listed below.

Getting dressed

- To put on pants, socks and shoes, bend at the knee to lift their legs and feet. Do not bend over at the waist to reach their legs and feet.
- Keep the back straight when putting on button-up shirts and coats. Do not twist at the waist. To tie shoes, bend their leg at the knee and place their foot on the opposite leg rather than bending down.

Brushing teeth

- Keep their back straight when they brush their teeth.
- Use 2 cups – 1 for rinsing and 1 for spitting. Bring each of them to their mouth instead of bending over to a low sink.

Going to the bathroom

- Bend at the knees to sit down and stand up from the toilet. Getting up and down from the toilet can be hard. Have someone help them at first if needed.
- Face forward when they clean themselves after going to the bathroom. Do not twist or bend at the waist.

Getting around at home

- Pick things up by bending at the knees, not their hips.
- Move household items that are too high or too low to reach. Make sure they can easily reach all of the things they need in the bedroom, bathroom, and kitchen.
- Sit in firm chairs with good support. Add an extra cushion to raise the height of the seat if needed. Avoid low or soft sofas and chairs that are harder to stand up from.

You can help prepare for OT by doing these things:

- Bring a change of clothes for ADLs like loose fitting pants, underwear, a button up shirt, socks and shoes.
- Bring items for grooming like a toothbrush and hairbrush.
- Think about your home and bathroom setup. This includes things like the type of shower you have, the height of the toilet, and how your child usually gets in and out of bed. Work with the therapist to plan a good way for your child to get around the bathroom, bedroom and home.

After Surgery: At Home

The goal is for your child to recover from surgery as quickly and safely as possible.

Care of the incision

Keeping the incision clean and dry is an important step in preventing an infection. Clean your hands with an alcohol-based gel or foam before changing the dressing or touching and cleaning the incision site.

- If your child has a bandage when they go home, the doctor will let you know how and when to change it. You will also have to change it if it has a large amount of drainage on it.
- Your child may have Steri-Strips, which are small strips of tape, or clear mesh tape over the incision. These most often fall off on their own in 1 to 2 weeks. You can keep the edges trimmed if needed. Use alcohol to clean the scissors before trimming the edges.
- Stitches are usually on the inside. This means the doctor does not need to remove them.
- If the doctor used skin glue, it may cause your child's skin to look a purplish color.
- Have your child change into clean clothes or change bed linens if they get soiled or wet from body fluids until the incision fully heals.

Pain control

Your child may need pain medicine during the first 1 to 3 weeks they are home. The doctor will give you a prescription. Your child will be able to gradually stop taking it over the next 2 to 3 weeks.

- Your child may take ibuprofen (Advil, Motrin or less costly store brand) for pain after surgery. Talk with the surgeon or nurse about the appropriate dose.
- Have your child change their position often, so they do not get sore from staying still too long. Walking often will help their soreness go away over time.
- Even 3 to 4 weeks after surgery, your child may still feel tired.
- Have your child think about and do things they enjoy like watching TV, listening to music, reading books or playing games with friends. This helps to take their mind off their discomfort.

See the Discomfort After Surgery section on page 39 for more information on managing pain.

Activities of daily living

Washing hair

Your child can wash their hair as often as they like. There are several ways they can do this until they are allowed to shower.

- If the bathroom sink is short enough, place a chair in front. Sit facing away from the sink and tilt their head back (like they do when they have their hair washed in a salon).
- Place a chair with the back facing the kitchen sink. Kneel on their knees (with the front of their thighs pressed against the back of the chair). Tilt their head forward and use the sprayer hose. Make sure they keep their back straight to maintain spinal precautions.

Taking a shower

Keep the incision clean and dry until the doctor tells you that your child is allowed to shower. Until then, they can give themselves a sponge bath. This helps to keep water away from the incision.

Once your child can shower, pat the incision dry with a clean towel to dry off.

- At first, they may feel dizzy or faint when they shower.
- To help with this:
  - Have someone nearby for the first few times they shower.
  - Place a waterproof chair in the shower. Have them sit on it during the shower.
  - Use lukewarm, not hot water.
- Use a mild soap around the incision.
- The doctor will let you know when your child may take a tub bath or go swimming.

Sleep and rest

Your child can sleep in their own bed at home. Use pillows for support like they did in the hospital. Have them take rest breaks often during the day, but increase their activity and walk more each day.

Eating

The doctor does not want your child to lose more than 10% of their body weight. Eating a well balanced diet and drinking enough fluids can help them:

- Heal faster.
- Maintain their weight.
- Regain their strength.

A balanced diet means they eat meals that have protein, whole grains, vitamins, minerals and fiber.

- Choose foods high in protein, iron and calcium such as peanut butter, eggs, meat, cheese, milk, yogurt and green, leafy vegetables.
- They can get extra calories and protein by drinking a nutritional supplement like Ensure or Boost, as directed by the doctor or nutritionist.
- Eat high fiber foods such as whole-grain cereals, whole-grain bread, fruits and raw vegetables.
- Drink six 8 ounce glasses of water a day to help prevent constipation.

To keep from feeling too full, your child can eat 5 or 6 small meals each day. This also can help them to get all the calories and nutrients their body needs.

Note to parents: If your child received tube feedings before surgery, continue them at home. If the doctor or nutritionist changed the feedings in the hospital, keep your child on the same feedings at home as directed. This allows for increased calories and protein for healing. Talk with the doctor before making any changes to your child’s tube feedings.

School

The doctor will let you know when your child can return to school. This is usually 2 to 3 weeks after surgery. The doctor can give you “Home Bound” paperwork that allows your child to do your schoolwork at home. When they return to school, your child may want to begin with half-days for the first week.

School books are heavy to carry. A couple tips include:

- Ask a friend to carry their books from class to class.
- Keep a set of books at home and at school so they do not have to carry them back and forth.
- Use a rolling backpack.
- If the school has stairs, they may ask for an elevator pass.

Physical activity

The doctor will let you know:

- When your teen may drive. They should always wear a seatbelt.
- When they may to go to physical education (PE). Let the doctor know what sports your child does, so they can let you know when your child may begin again. They may be able to begin some light exercise, such as swimming in 2 to 3 months.
- When it is OK to lift anything over 10 pounds.
- When it is OK to swim in lakes, oceans, streams and rivers. Your child cannot do this until the incision is fully healed.

Other tips include:

- Walk, walk and walk! This will help your child get better faster. They can go up and down stairs but should use a railing to help them feel more secure.
- It is often easier to sit in a higher, firm chair rather than in a low, soft chair.
- Bend at the knees and hips if they need to pick something up off the floor. Do not bend or twist at the waist.

When to call your child’s surgeon

You or your child will need to call your surgeon if they have:

- A temperature of 101°F and do not also have a cold, flu or other illness
- Increased redness, swelling, tenderness, pain or warmth at the incision sites
- Drainage or bad smell coming from the incision sites
- Open areas along the incision line
- Pain that does not get better with pain medicine
- Numbness or tingling in the arms, legs or feet
- Change in bowel or bladder control
- Vomiting (throwing up)
- Any questions or concerns about how they feel

Notes

Discomfort after Surgery

Pain management

Pain management is very important. The doctors and staff will work with you and your child to help prevent or decrease pain and discomfort when possible. Since discomfort is a normal part of spinal fusion surgery, we will use several methods to help manage pain. These include medicines, activity, rest, comfort measures and diet.

We will work with you to ensure your child gets enough relief to sleep, turn or walk as needed. Let the nurse or doctor know if your child is not any better after using these methods.

A note to parents about pain management

You are a vital part of your child's treatment, including pain management. See below for more information and tips to help your child.

Your child has the right to:

- Receive care that will decrease or prevent discomfort.
- Be told the truth about their discomfort.
- Tell others if they hurt and what they think will help make it better.
- Cry or object when anything hurts or upsets them.
- Have questions answered in words they can understand.
- Keep their bed a safe place, when possible.
- Watch during a procedure if they want to do so.
- Be with a parent when in pain, if possible.

What you can do to help us help your child:

- Tell us as soon as your child is uncomfortable.
- Ask your child's doctor or nurse what to expect.
- Ask about the plan to treat your child's discomfort.
- Tell us what helped your child in the past when they were uncomfortable.
- Tell us what you think we can do to help your child.
- Tell us if what we are doing is not working.
- Work with staff to try new methods to make your child more comfortable.
- Let us know if you have any questions.

We learn about your child's pain by:

- Listening to what your child says.
- Watching what your child does.
- Noting changes in your child's body.
- Talking with you about what you see.

To help your child tell us about their pain, we use different "scales" to measure pain. Please reference page 22. Your child is the best person to talk about what hurts them. While you can help us in keeping your child as comfortable as possible, they are the expert on how their pain is. Please ask the nurse to show you the tool we use for your child.

We also ask you to help us look for changes in your child's behavior such as:

- Crying or fussing
- Holding, touching, guarding or rubbing the painful area
- Talking less or being quiet
- Sleeping more or less
- Eating less
- Does not want to move
- Making a pain face (grimace)
- Sweating

What can we do to help?

Medicines

There are many medicines that help relieve pain and they are given in different ways. Your child's doctor will talk with you about the medicine that is best for your child. Let your child's nurse or doctor know if you have concerns or questions about your child's pain medicines.

Play and relaxation

There are also other ways to help your child not think about their discomfort. Our staff is trained in how to use play, distraction and relaxation with children. Here are some ideas you might want to try:

Babies

- Rocking or holding
- Breastfeeding or using sucrose during painful procedures
- Swaddling your baby
- Skin to skin contact or kangaroo care
- Singing and music
- Listening to soft words or sounds
- Gentle massage
- Pacifier
- Favorite toy
- Decreased light, noise and other external stimulation

Toddlers and preschoolers

- Rocking or holding
- Singing or listening to music
- Telling stories
- Watching videos or TV
- Blowing bubbles
- Pop-up books and toys

School-age children and teens

- Talking about what helped in the past
- Knowing what to expect and having a plan for difficult situations
- Breathing deeply and slowly
- Watching videos or TV
- Playing electronic games or listening to music
- Imagining he is in his favorite place
- Visits with friends
- Massage

See the ‘Making Needles Hurt Less’ handout in the Resources section of this handbook. You know your child best. Please tell us if there is anything else we can do to help decrease your child’s pain.

Notes

Inpatient Rehabilitation

Inpatient rehabilitation

If the doctor wants your child to stay at the hospital for therapy after surgery, you may go to the Children's comprehensive inpatient rehabilitation unit (CIRU). A team of pediatric-trained staff, led by a physiatrist or rehabilitation doctor, and a case manager, will:

- Support you, your child and your family during your rehab stay.
- Teach your child to be as independent as possible.
- Teach you to care for your child at home.

This can be a very stressful time for your family. Feel free to talk with our social worker and/or chaplain, take part in support groups and connect with family and friends.

Team meetings

Your child's team meets weekly. The meetings are an important part of your rehab stay. Team members include you, your child if they are able, and your child's doctors, therapists, nurses and team members. The purpose of the meeting is to:

- Talk about your child's treatment plan and their progress, needs and challenges.
- Find out about your goals for your child.
- Help prepare you for going home.
- Answer your questions.

A case manager or social worker will let you know when your child's first team meeting will be.

- Make plans to attend the first meeting.
- Each child has a 5 to 10-minute time slot. If you cannot attend a meeting, the CIRU case manager can give you an update.
- The parent attends only the first meeting unless the child/teen or the parent ask to attend another meeting. Your child's case manager will update you after every team meeting.

You or your child may feel uncomfortable asking questions at the full team meeting. Tell the case manager if you would rather meet with a smaller group. Tell us how we can help you feel as comfortable as possible. Ask your child's nurse or therapist if you have any questions about your child's team meeting or treatment plan.

Your child's rehab schedule

Our rehab team will work to create a program to meet your child's needs. Some of your child's rehab activities may be the same as other patients on the unit. Others may be different.

- Therapy sessions are 1 hour, 45 minutes, or done as two 30 minute sessions.
- Therapy is provided 7 days a week, including holidays.

A sample schedule is listed here:

- 7 to 8:30 a.m. - activities of daily living, medicines and tube feedings (if needed)
- 8 to 8:30 a.m. - breakfast
- 8:30 a.m. to noon (12 p.m.) - individual or group therapy sessions
- Noon to 1 p.m. - lunch group or break time in your child's room
- 1 to 4 p.m. - individual or group therapy sessions
- 4 to 5 p.m. - group time or break time in your child's room
- 5 to 6 p.m. - dinner in your child's room
- 6 to 8 p.m. - family time, evening programs
- 10 p.m. - lights out

Therapy sessions may include:

- Activities of daily living, such as washing, dressing and brushing teeth
- Transfers into and out of bed
- Transport to and from room when needed
- Diaper changes or bathroom visits
- Caregiver training
- Your child also may take part in activities, such as exercises, cooking, study time, pet therapy, community outings, and craft and peer groups.

The evening before therapy, your child usually will receive their schedule for the next day. Have your child ready on time. Bring them to the assigned area for their therapy. This will allow your child to be treated on time and for the full session. Parents can participate when available and only if they have been trained to transfer their child.

We do our best to keep your child's daily schedule the same during the week. There may be times when this is not possible. Some reasons why your child's schedule may change include:

- Special tests or procedures
- Visits from doctors
- Nursing care or medicine schedules
- Your child is sick
- Therapeutic leaves of absence (TLOA)
- Special events

There are times when more therapy does not equal better therapy. After a long hospital stay, your child's energy level may be lower than normal. The rehab team may find that your child needs more rest breaks. If so, we will give your child breaks during the treatment day. This can help your child get the most benefit from therapy sessions.

Weekend schedules

Your child will also have therapy during weekends and on holidays. There may be a few changes from the weekday schedule:

- The day begins later, which allows you and your child to sleep in.
- Your child may also have group or individual therapy sessions during the day.
- We offer special events and activities during weekends and on holidays:
  - Pet therapy visits happen every other weekend.
  - Chapel services are offered Sundays.
  - Movies may be shown on Saturdays.

Evening programs

All hospital patients are invited to take part in evening activities when they happen. A list of “Hospital Happenings” is posted in the playroom.

Therapy after discharge

Your child’s therapy will continue after their inpatient rehab stay. Your child’s case manager can help you find services near your home. Children’s is proud of the scope of care that we offer.

- Day Rehabilitation program: Children’s offers a full day program of physical, occupational and speech-language therapy. We also provide school, nursing, case management and social work services.
  - The therapy day is structured like a child’s school day, 9 a.m. to 3 p.m., Monday to Friday. This allows your family to spend the evening at home.
  - Someone from Day Rehab can meet with you to tell you more about the program.
- Outpatient Rehabilitation program: There are 9 locations around Atlanta to help your child continue therapy.
- Sports Medicine program: There are 12 locations around Atlanta to help your athlete return to sports following spine surgery.

Rehabilitation physician follow-up

Your child may be scheduled for follow-up visits at the Children’s rehab clinic. This may happen 6 to 8 weeks after discharge to home. Your child will see their doctor, who will talk with you about further treatment.

Notes

Resources

Pre-surgery checklist

1 month before surgery

- Check with your child’s school about home teaching and start paperwork.
- A care coordinator will help you:
  - Schedule a 2 week pre-op visit with your child’s doctor.
  - Schedule pre-op CT scan and/or MRI if needed.
  - Schedule pre-op anesthesia visit and tour.

Before surgery

- Pre-op visit with your child’s doctor
- Pre-op CT scan and/or MRI if needed
- Pre-op anesthesia visit
- Hospital tour and child life visit
- Pack—find a list of what to bring on the next page
- Nothing to eat or drink after midnight
- Use the CHG wipes as taught in pre-op clinic

What to bring

We want your child to be as comfortable as possible during their stay. To bring some comforts from home, here is a checklist of items you might want to pack.

- Comfortable, loose clothing or PJs*
- Bathrobe*
- Extra underwear
- Comfortable shoes or slippers
- Socks
- Favorite towels and washcloths*
- Favorite pillow or body pillow*
- Favorite blanket*
- Laptop or iPad (the hospitals have free Wi-Fi)
- Phone, charger and headphones
- Favorite movie (each patient room has a DVD player)
- Toothbrush and toothpaste
- Mouthwash
- Hairbrush or comb
- Soap or skin care items
- Make-up
- Deodorant
- Feminine supplies
- Lotion
- Hair ties or headbands
- Stuffed animals*
- Chewing gum

*Only bring items that can be washed before coming to and after leaving the hospital to decrease your child’s risk of infection.

Traveling families and visitors

We know having a child in the hospital is a stressful time. That is why we do everything we can to help patients, parents and visitors feel comfortable, safe and secure.

Below are area hotels that offer special hospital rates to patients' families at Egleston.

*Courtyard by Marriott, 1236 Executive Park Drive - 404-728-0708

*Emory Conference Center Hotel, 1641 Clifton Road - 404-712-6700 (free shuttle to Egleston)

*Hampton Inn, 1975 North Druid Hills - 404-320-6600

*Courtyard Marriott/Decatur, 130 Clairemont Avenue - 404-371-0204

*Holiday Inn Express at Emory, 2183 North Decatur Road - 404-320-0888

Quality Inn/Northlake, 2155 Ranchwood Drive - 770-491-7444

Extended Stay America Atlanta-Northlake, 3300 Northlake Parkway - 770-938-0408

*University Inn at Emory, 1767 North Decatur Road - 404-634-7327

*Identifies accommodations nearest the hospital

Below are area hotels that offer special hospital rates to patients' families at Scottish Rite.

Courtyard Atlanta Perimeter Center, 6250 Peachtree Dunwoody Road - 770-393-1000

Extended Stay America Hotel, 1050 Hammond Drive - 770-522-0025

*Fairfield Inn & Suites Atlanta Perimeter, 1145 Hammond Drive - 770-350-0000

Hilton Atlanta Perimeter Suites, 6120 Peachtree Dunwoody Road NE - 770-668-0808

Holiday Inn Express Atlanta Perimeter Mall, 765 Hammond Drive - 404-250-4450

Home2 Suites, Perimeter Center, 6110 Peachtree Dunwoody Road - 770-828-0330

*Hyatt House Atlanta Perimeter Center, 5785 Peachtree Dunwoody Road - 404-968-2400

*Sheraton Atlanta Perimeter North, 800 Hammond Drive - 404-564-3000

*The Westin Atlanta Perimeter North, 7 Concourse Parkway NE - 770-395-3900

*Identifies accommodations nearest the hospital

Talk with your child's social worker or call the Family Support Services office from a hospital phone.

- Egleston hospital: 404-785-6250 or dial extension 5-6250 from a hospital phone
- Scottish Rite hospital: 404-785-2010 or dial extension 5-2010 from a hospital phone

Visit choa.org/visitors to find more information. This includes visitor guidelines, transportation and lodging resources.

Parking passes

You can buy parking coupon booklets from the parking booth attendant for $5. Each booklet contains 5 tickets. Each ticket allows 1 vehicle in and out.

Family library

The library offers:

- Health information for patients and families
- Library staff to help you find what you need
- Access to the Internet, e-mail and medical databases
- Books and DVDs that you can check out

The Egleston Family Resource Library

404-785-1611 or extension 5-1611 from a hospital phone

The Children's Max Brown Family Resource Library at Scottish Rite

404-785-2192 or extension 5-2192 from a hospital phone

Notes

Making needles hurt less

You play a very important role in helping your child through painful procedures. At Children’s Healthcare of Atlanta, you and your healthcare team can work together to help your child learn about and better manage needle sticks.

PREPARE	Use simple words to tell your child what is going to happen on a level they can understand.
USE SOFT LANGUAGE	Avoid using words that might scare your child like shot, burn or sting. Use softer words with a slow, calm voice. You might say, “The nurse will gently slide a small tube into your arm,” or “It is time to get medicine in your arm. You may feel a pinch.”
BE HONEST	Avoid making promises you cannot keep, such as, “I promise it will not hurt.” Children need truthful information to build trust in you and others.
TELL	Tell the hospital staff what has helped or not helped your child in the past. (Also tell your child it is not their fault that they are going through something painful. Young children can see pain as a form of punishment.) Tell your child their job is “to hold their arm still”– this may help your child feel more in control.
REQUEST	Ask for cold spray or local anesthetic cream which numb the skin before needle sticks. You may also request that your child be taken to the treatment room (if one is available) for needle sticks so they can rest and relax in their bed.
OFFER CHOICES	Give your child a sense of control by offering choices before and/or during the procedure. You may ask, “Would you like to watch or look away?” or “Would you like to count or take some deep breaths when it is time to start?”
BE AWARE	Try to remain calm. If you are upset, your child may become more fearful. If you are not able to support your child through a painful procedure, it is OK to ask for help or leave the room.
COMFORT	Hold your child’s hand or hold them in a comforting position if possible.
PRAISE	When giving praise, avoid saying “good boy” or “good girl.” Instead, comment on your child’s positive behaviors, such as “You did such a good job holding still!” or “I like the way you let us know how that felt!” If you label your child as being a good boy or good girl for not crying, the next time your child cries, they may think they have failed in some way.
SUPPORT	Tell your child that crying or being mad is OK. Sometimes crying or expressing emotions is what a child needs to do to get through painful events.
OFFER	

IDEAS

You can talk with your child about different ways to help them get through a painful procedure such as:

- **Breathing** with slow, deep breaths or using bubbles.
- **Squeezing** someone’s hand if they feel something.
- **Counting** before or during the needle stick.
- **Looking** at something they like (such as TV, a book, magic wand, etc.).
- **Imagining** their favorite place or doing something they like.
- **Listening** to their favorite music or singing.
- **Talking** to the people around them about something they enjoy.
- **Remembering** to hold still during the needle stick.

Spinal fusion surgery: Cleaning with CHG cloths

What are CHG cloths?

CHG (chlorhexidine gluconate) is a special kind of skin cleaner.

- You will use it at home to wash your child's skin the evening before surgery (pre-op).
- It can be used in children and teens but cannot be used for babies younger than 2 months old.

Why do I need to wash with CHG wipes before surgery?

- CHG removes more germs from the skin than regular soap and water.
- This means there is less chance of infection during and after surgery.

NOTE: Do not use CHG cloths if your child:

- Is sensitive to CHG.
- Has skin problems such as burns, rashes, eczema, or open wounds or dressings that you cannot remove.

How do I use CHG cloths?

Use CHG cloths to wash your child's skin **the evening before** you come to the hospital. Our staff will wash your child's skin again just before surgery. To help prevent infection and prepare your child's skin for surgery, follow these guidelines.

Before using CHG cloths:

1. Remove all jewelry such as earrings, necklaces and bracelets. Keep them off until after surgery. Talk with your child's nurse if you are worried about taking any jewelry off for cultural or religious reasons.
2. To help decrease germs, clean and trim your child's fingernails and toenails. Also remove any nail polish.
3. Wash first with regular soap and shampoo. Rinse and dry well using a clean towel.
4. Do not apply any lotions, moisturizers or makeup after the shower or bath. These products may attract dirt to the skin.

NOTE: Do not use the cloths on your child's face, ears, eyes, nose, mouth or private parts (genital area). If the cloths do touch these areas, rinse them well with clean, warm water to prevent irritation.

To use CHG cloths:

1. Use CHG cloths to wipe/clean the skin (see table below).
2. Use at least 2 cloths.
3. Do not rinse the area with water unless a rash or redness happens. Your child's skin will feel sticky for about 3 to 5 minutes.
4. Let your child's skin air dry – do not use a towel to dry the skin.

	Less than 10 kg (21 pounds or less)	**10 to 30 kg (22 to 66 pounds)**	**More than 30 kg (67 pounds or more)**	**Teens and adults**
CHG cloth 1	Jaw to chest, abdomen (belly), arms and back	Jaw to chest, arms and abdomen (belly)	Jaw to chest, abdomen (belly) and arms	Jaw to chest
CHG cloth 2	Both legs, buttocks and perineum*	Back and buttocks	Right leg	Both arms
CHG cloth 3	--------------------------	Both legs	Left leg	Abdomen (belly), groin and perineum*
CHG cloth 4	--------------------------	Perineum*	Back	Right leg
CHG cloth 5	--------------------------	--------------------------	Buttocks	Left leg
CHG cloth 6	--------------------------	--------------------------	Perineum*	Back and buttocks

***Please note:** the perineum is the area between the anus (where stool comes out) and the private parts.

After using CHG cloths:

1. Do not flush the cloths down the toilet. Throw them away in the trash.
2. Dress in clean, washed pajamas.
3. Make sure your bed linens are clean and washed before going to bed.
4. Wash any comfort items, such as blankets or stuffed animals that you may bring to the hospital.
5. Do not take a bath or shower the morning of surgery.
6. Our staff will wash your skin again just before you go to surgery. We will also give you a clean hospital gown and surgical hat to wear after your wash.

Video-on-demand TV channel

For patients and families at the hospital, the on-demand system has videos to help you take care of your child’s health or illness. All videos are free. You can watch videos about health topics such as:

- Baby and childcare
- Child safety and CPR
- Health topics to help care for your child in the hospital and at home, such as asthma, diabetes, cast care and surgery
- Nutrition, bottle feeding and breastfeeding

The system also contains videos for children and teens. Many videos are available in Spanish.

To watch a video:

- Turn on the TV.
- Use your bedside phone to dial 5-5093 at Egleston or 5-2019 at Scottish Rite.
- Browse on screen options by pressing ‘2’. The menu contains a list of on-demand videos for you to view.
- Follow the prompts as directed. Use TV remote to change the channel.
- Press ‘#’ to begin your video or browse.
- Hang up the phone when the video begins or when you finish browsing.

If you have questions, ask your child’s nurse.

Emergency family assistance

If you need emergency help with needs such as meals, lodging or transportation, talk with your child’s social worker or go to the Family Support Services office. You may need to fill out a form for assistance. The form also needs to be reviewed by someone outside of Children’s.

- The Family Support Services office at Egleston is open Monday to Friday, 8:30 a.m. to 5 p.m. The phone number is 404-785-6250 or dial 5-6250 from a hospital phone.
- The Family Support Services office at Scottish Rite is open Monday to Friday, 8:30 a.m. to 5 p.m. The phone number is 404-785-2010 or dial 5-2010 from a hospital phone.

If you need help right away when the office is not open, ask your child’s nurse to page the evening or weekend social workers.

Financial assistance

If you need help with insurance matters or have other questions about your child’s hospital bill, please see the chart below.

For questions or concerns about:	Talk with:	Contact:
1. Insurance coverage	A financial counselor	Patient Registration
2. Medicaid applications	A Medicaid caseworker	Patient Registration
3.State and federal programs such as Supplemental Security Income (SSI— disability for children)	Your child’s social worker	Ask your child’s nurse or see the social worker for your child’s unit

HeLP Onsite Legal Assistance Program

The Health Law Partnership (HeLP) is a program sponsored by Children's, Georgia State University School of Law and Atlanta Legal Aid Society. It provides free legal help to qualified patients and families with legal issues that impact the patient's health. This program can address housing, education, denial of benefits and many other issues. For more information, call 404-785-2005 or dial extension 5-2005 from a hospital phone.

Helpful websites

You may find this list of websites helpful when searching for more information about scoliosis and spine surgery.

Orthopaedic-related sites:

The Children's Orthopaedics Program
choa.org/medical-services/orthopaedics

American Academy of Orthopaedic Surgery
aaos.org

American Physical Therapy Association
apta.org

The Pediatric Orthopaedic Society of North America
posna.org

Scoliosis Research Society (SRS)
srs.org

Others:

Children's Healthcare of Atlanta
choa.org

Atlanta Hotel Guide
atlanta.hotelguide.net

Centers for Medicare and Medicaid Services
cms.hhs.gov

Georgia Peach Care
peachcare.org

Medicare
medicare.gov

MedlinePlus

nlm.nih.gov/medlineplus/medlineplus.html

Children's Healthcare of Atlanta has not reviewed all of the sites listed as resources and does not make any representations regarding their content or accuracy. Children's Healthcare of Atlanta does not recommend or endorse any particular products, services or the content or use of any third party websites, or make any determination that such products, services or websites are necessary or appropriate for you or for the use in rendering care to patients. Children's Healthcare of Atlanta is not responsible for the content of any of the above-referenced sites or any sites linked to these Sites. Use of the links provided on this or other sites is at your sole risk.

Glossary

Allograft: The transplant of a bone from one person to another.

***Anesthesia*:** Medicine that causes a deep sleep during surgery.

Autograft: Bone taken from one part of the body to another in the same person.

Bone graft: Surgery to place new bone or bone substitutes into spaces around a bone defect.

CT scan: A CT scan uses advanced X-ray technology to take cross-sectional images, sometimes called "slices," of the body.

Foley catheter: A small tube used to drain urine from the bladder.

Hemovac*:* A drain placed in the incision area during surgery. It removes blood or other fluids that might build up in this area.

Idiopathic: No known cause.

***Incentive spirometer*:** A breathing device that helps patients take a deep breath in order to keep the lungs healthy.

***Incision*:** A cut made in the skin for surgery.

***Intravenous (I.V.)*:** In the vein; refers to a small needle or plastic catheter placed in the hand, foot or arm to give fluid and medicine.

Kyphosis: A curving of the spine that causes a bowing or rounding of the back.

***Magnetic resonance imaging (MRI)*:** A test that uses large magnets, radiofrequencies and a computer to produce detailed images of parts of the body.

Neuromuscular: The system of the body dealing with the nerves and muscles.

Occupational therapy (OT): A type of therapy used to improve basic movement and self-care abilities, called activities of daily living or ADL's.

Orthopaedic: The type of medicine and surgery that focuses on injuries and diseases of the body's bone and muscle system.

Pathology: The branch of medicine concerned with the cause, origin and nature of disease, including the changes occurring as a result of disease.

Patient-controlled analgesia (PCA) pump: A device used to help manage pain. It gives a patient control over his own pain relief.

***Physical therapy (PT)*:** A type of therapy used to improve movement, strength, coordination and balance.

Scoliosis: A sideways curve of the spine.

Vertebra: Any of the bones in the back that make up the spinal column.

***X-ray*:** A picture of the inside of the body made with special radioactive rays.

Notes