Dear patient and family,

This handbook is for you to learn more about your child's spine surgery. Please read it before your appointments and hospital stay. There are spaces for you to write down your questions for the care team. Bring the handbook and your questions to the hospital and all doctor's appointments.

You should visit choa.org/medical-services/orthopedics/scoliosis-and-spine-program/scoliosis/spine-surgery to learn how to get ready for spine surgery. Watch the video and review this spine surgery handbook.

We hope this helps you understand what happens before, during and after your child's surgery. We will guide you through the path to recovery. You can find words in **bold** in the Glossary on page 67.

This handbook should not replace instructions from your child's doctor and healthcare team. It is not meant to be medical advice or a complete source of all information about their treatment plan. This handbook provides information on what you and your child can generally expect throughout the process.

Your child's doctor is the best source of information 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 Orthopedics 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 is among the top pediatric orthopedic programs in the country. We take care of babies, children and teens with:

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

We also have services for:

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

Our program includes a team of specialists who work together with a surgeon to help your child. The team includes:

- Anesthesiologists
- Infectious disease specialists
- 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. You will get a survey from Children's after your visits. Please complete the survey as soon as possible. We value your input on your family's experience at Children's.

Important phone numbers

Please write down the name and phone number for each of these.

Arthur M. Blank Hospital **Scottish Rite Hospital**	404-785-KIDS (5437)
Spine Program Manager:	404-785-7575
Orthopedic surgeon (spine doctor):	
Pediatrician or family doctor:	
Drug store or pharmacy:	
Emergency contact:	
Nearest emergency department (ED):	

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

In case of an urgent concern or emergency, call 911 or go to the nearest emergency department right away.

Orthopedic 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.

- **Orthopedic spine surgeon**: A pediatric orthopedic surgeon who has expertise in the assessment, medical and surgical treatment of children, teen and young adult spinal conditions. They are in charge of the team caring for your child before, during and after surgery.
- **Pediatric orthopedic resident:** A surgeon in training for orthopedic surgery. They graduated from medical school and completed a surgical internship. They are in a subspecialty portion of orthopedic specialty training to prepare for a career in orthopedic surgery.
- **Pediatric orthopedic fellow**: An orthopedic surgeon who is completing training in the field of pediatric orthopedic surgery. They graduated from medical school and completed a surgical internship and orthopedic residency training. They are doing pediatric orthopedic subspecialty training to prepare for a career in pediatric orthopedic surgery.
- **Pediatric anesthesiologist**: A doctor trained to give children and teens **anesthesia**. Anesthesia is the medicine that causes deep sleep during surgery. This doctor also monitors your child during the surgery.
- **Physiatrist**: A doctor trained in physical medicine and rehab. This doctor oversees your child's medical care and therapy if they stay in the hospital for therapy after surgery.
- **Nurse**: A registered nurse (RN) trained to provide care for your child.
- **Physician assistant (PA) or nurse practitioner (NP)**: A provider with an advanced medical degree who works with the surgeon to help manage your child's care.
- **Registered dietitian**: A team member who checks your child's food and fluid intake. They follow your child's overall growth. They can teach you about the best food choices for your child's recovery. They are also called clinical nutritionists.
- **Child life specialist**: A team member trained to help your child and family cope with the stress of being in the hospital. A child life specialist can teach you and your child about surgery and ways to cope with fear or pain.
- **Social worker**: A team member trained to support 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 trained to assess 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 trained to help your child be more independent in caring for themself after surgery. This can include dressing, brushing their teeth and combing their hair.
- **Orthotist**: A team member who designs, builds and fits braces to support body parts. This includes braces for your child's 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 clinician who helps to plan and coordinate your child's care for when you go home. They also provide resources for 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 in a handy place while you are in the hospital.

Orthopedic spine doctor

Name: ____ Phone: ________________________

Nurse

Name: ____ Phone: ________________________

Physical therapist (PT)

Name: ____ Phone: ________________________

Occupational therapist (OT)

Name: ____ Phone: ________________________

Child life specialist

Name: ____ Phone: ________________________

Case manager

Name: ____ Phone: ________________________

Chaplain

Name: ____ Phone: ________________________

Social worker

Name: ____ Phone: ________________________

Patient safety

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

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

We know that you and your child are going through many new things. Please speak up and ask a staff member if you have a concern or question about anything.

- If you do not understand a consent (permission) form or any other part of your child's care, please ask us to explain again.
- It is your right to have things explained to you in a way that you can understand.
- If you think that your child is not acting normally or you have other concerns about how your child looks or feels, please tell us.

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

Please do these 6 things regularly to help keep your child safe:

1. **Wash your hands with soap and water or use alcohol-based gel or foam.** Wash your child's hands as well when needed:
    - When entering and exiting your child's room.
    - Before and after eating.
    - After helping your child in the bathroom or changing a diaper.
2. Everyone who comes to see your child should wash their hands, including hospital staff. Please speak up if we do not do this.
3. Keep the identification (ID) band on your child. Tell a staff member right away if it comes off.
4. Hospital staff should check your child's ID band when they:
    - Give medicines.
    - Collect blood or urine.
    - Do procedures.

    Please speak up if we do not do this.
5. Keep your child's bed or crib side rails up and the bed in its lowest position. This will help prevent falls.
6. Please speak up. Ask a staff member any time you have questions or concerns. Be involved in making decisions about your child's care. Write down important information and questions so you remember them later.

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

All patients in the hospital must wear an ID band. This helps keep your child safe. It ensures that staff treat the correct patient. Every staff member should read your child's ID band even if they know your child.

- Keep your child's ID band on. Tell staff right away if it comes off.
- Our staff will involve you when we ID your child. We will ask you to verify your child's name, date of birth, and we will check your child's ID band before:
  - Giving medicines.
  - Giving or collecting breast milk for babies.
  - Giving blood products.
  - Collecting specimens and labs.
  - Doing treatments or procedures.
- If someone does not check the ID band first, please speak up and ask them to do so.
- Children with allergies also wear a red band.
- Children allergic to latex also wear a green band.
- Children at risk for falls also wear an orange band.

Why do we need bed rails in the hospital?

- Many children in the hospital are at risk for falls because of the medicines and procedures.
- A fall can make a hospital stay longer than needed.

To keep your child safe:

- Keep the bed rails up and locked in place.
- Please ask a staff member if you do not know how the bed rails work.

What if a machine is beeping?

Most of our equipment have alarms to keep your child safe.

- Alarms tell your team that something needs to be checked.
- Please leave the alarm on and push the nurse call button to get a nurse. Do not turn off alarms.

Other safety tips

Prevent falls

- Always tell your child's nurse if you are leaving the room. Do not leave your child alone without telling anyone.

- Keep the bed at its lowest setting to the ground.
- Your child should sleep in the bed. Do not allow them to sleep on the couch or in the chair.
- Have your child wear shoes or non-slip socks when they get out of bed. Ask a staff member for a pair if you do not have them.
- Do not allow your child to:
  - Play with any medical equipment, such as monitors or pumps.
  - Ride on I.V. poles.
  - Run in the hallway.
  - Climb on furniture.

Medicine safety

- Tell the doctors and nurses about allergies or drug reactions your child may have.
- Keep a complete and updated list of the medicines your child takes. This includes:
  - Prescriptions for doctors.
  - Over-the-counter medicines.
  - Herbs and supplements.
- You should know these things about each of your child's medicines:
  - The name of the medicine.
  - Why it is used.
  - When and how to give it.
  - Any side effects.
  - Any other medicines, foods or drinks to avoid when taking it.
- Share this list with all of your child's doctors.
- Ask your child's nurse or doctor about any medicines that are different or new. This includes how they look and when the nurse gives them to your child.

Test results

- Ask for the test results and for someone to explain them to you.
- You should not assume tests are OK if you do not hear from your doctor.

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 on our hands. Germs are bacteria and viruses that cause infections. Hand hygiene is one of the most important things that you and your family can do to stay healthy. Teach your family, babysitters and childcare workers about the importance of good hand hygiene.

Good hand hygiene helps prevent the spread of infections.

- Hands can carry germs that cause colds, pinkeye, diarrhea and more 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 hands to your nose, mouth, eyes or an open wound.

Five simple steps for washing you and your child's hands:

1. **Wet**: Use warm running water.
2. **Lather**: Use soap and rub your hands together until you get lots of bubbles. Check the bottle and make sure it is labeled antibacterial if your child's doctor tells you to use this type of soap.
3. **Wash**: Rub your hands together, washing your whole hand for at least 20 seconds. This includes all of the fingers, both thumbs, between and under fingernails, back of hands, palms and wrists.
4. **Rinse**: Rinse your hands 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 a cloth towel. Use a dry paper towel to turn off the sink.

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

You should **use soap and water** when you:

- See dirt or grime on your hands.
- Handle uncooked meats or prepare food.
- Change diapers or use the bathroom.

You should not use alcohol-based gel or foam before you:

- Prepare food.
- Touch your or your child's eyes or mouth.
- Put in or take out contact lenses.

Clean your hands **before** you:

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

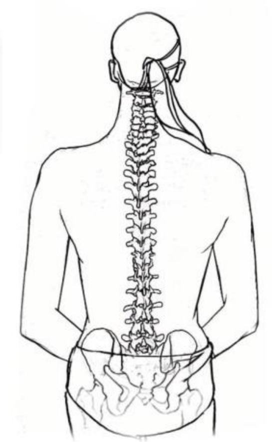
Clean your hands **after** you:

- Go to the bathroom.
- Help your child use the bathroom or change a diaper.
- Handle uncooked food.
- Touch trash 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 leave your child’s room. Also wash your hands before you touch 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 like the letter S or C rather than a straight line.

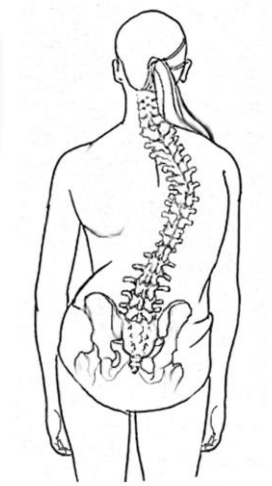
What is kyphosis?

Kyphosis is a forward curve of the spine that causes the back to be bowed or rounded.

What causes idiopathic scoliosis and kyphosis?

Both scoliosis and kyphosis are found in families. There is no known cause for them. Things that **do not** cause scoliosis or kyphosis include:

- Bad posture.
- Heavy backpacks.
- Poor diet.



Spinal curvature

What are the signs of scoliosis and kyphosis?

Your child may have one or more of these signs.

When standing up:

- One shoulder blade sticks out more than the other.
- One shoulder is higher than the other.
- One hip is higher than the other.

When bending forward:

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

Scoliosis and kyphosis most often do not cause back pain. Tell your child's doctor if they have pain.

What tests check for scoliosis and kyphosis?

Two common tests include:

- A scoliosis and kyphosis screening exam that is done by a trained expert like a nurse, advanced practice provider or doctor. They are looking for signs of scoliosis or kyphosis.
- **X-rays** of the back and spine that:
    - Show the doctor if your child has a curve in their spine.
    - Measure the amount of curve in your child's back. The curve is measured in degrees.
    - Diagnose the type of scoliosis.
    - Tells the doctor about your child's growth. This allows the doctor to assess if the curve will get worse. The doctor will give you a plan based on whether your child is still growing.

What is the treatment for scoliosis and kyphosis?

A bone and muscle doctor called an orthopedic surgeon most often treats scoliosis and kyphosis. Treatment depends on the degree of your child's curve and how much growing they have left to do. Treatment is not always needed.

The doctor will talk with you about treatment options if needed. Treatment may include:

- Observation. The care team checks for changes in the curve with an X-ray 2 or 3 times a year.
- Bracing. Your child wears a form-fitting brace each day for a certain number of hours.
- Surgery. Your child has surgery to adjust the bones in their spine. This helps prevent the curve from getting worse and decreases deformity.

Surgery is specific to each child's **pathology.**

- Growth modulation surgery uses the spine's growth to improve the deformity.
- Curve modulation surgery is a series of surgeries that decrease spinal deformity. This allows for spinal growth.
- Spinal fusion is a surgery that decreases spinal deformity and stops the curve from getting worse.

Spine surgery

Orthopedic surgeons offer options to meet the needs of children and teens with spine conditions. Your child's doctor will talk with you about the best surgery choice for your child. This could include:

- Spinal fusion
- Growing rods
- Vertical expandable prosthetic titanium rib (VEPTR)

What is a spinal fusion?

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

There are 3 ways to do spinal fusions.

1. Anterior. This is done on the front part of the spine through an **incision** in your child's side.
2. Posterior. This is done on the back of the spine through an incision in your child's back. This is the most common.
3. Anterior-posterior. This is 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 their back.
- The type of spinal curve your child has and how flexible the curve is.

All 3 methods use pieces of bone, metal rods, screws and hooks to connect the bones together.

- The metal rods and screws help keep the bones in the right place and hold them straight.
- The **bone graft** is like a bridge that grows into the spaces between the bones. This connects them together.

The bone graft can come from:

- A piece of bone from your child's hip area. This is called an **autograft.**
  - Your child will have an incision over their hip area.
  - It should not affect your child's ability 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.

What is a growing rod and VEPTR?

Growing rod and VEPTR surgeries use special instruments. These procedures allow the surgeon to adjust the instruments so the spine can continue to grow. They temporarily:

- Help to correct the spinal curve.
- Help prevent progression of the curve without fusion.

Your child has a procedure every 6 months to lengthen the instrument, so the spine continues to grow. These procedures are only used when a child has a lot of growing left to do. Your child's doctor will discuss with you the best treatment options.

What is a magnetic expansion control (MAGEC rod)?

MAGEC growing rods are rods that a surgeon can put into your child's back. The surgeon can lengthen the rod with a remote control applied to the skin. They do not need to do multiple surgeries.

What is the process for growing rods?

Growing rods allow for controlled growth of the spine. Metal rods are attached to the spine during surgery. Then they are lengthened over time during a simple outpatient procedure. This is done through the back of the spine.

Your child comes back to clinic about every 6 months to have the rods lengthened about 1 centimeter to keep up with their growth. Some children have to wear a brace to protect the rods. The doctor removes the rods and does a formal spinal fusion surgery when the spine is done growing.

What is a VEPTR?

A vertical expandable prosthetic titanium rib (VEPTR) is a curved metal rod placed next to your child's ribs near the spine. It helps keep the spine straight and can expand so their lungs can grow. This procedure is recommended between the ages of 18 months and 5 years.

What is the process for VEPTR?

VEPTR surgery can help patients 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.

After the surgery:

- Your child will stay in the hospital for a few days.
- Every 4 to 6 months, the metal rod is expanded. This happens until your child's bones stop growing. Expanding the rod helps the chest grow. This is important for the lungs, heart and other body parts.
- Your child may need to wear a brace after surgery.
- Your child will be able to do physical activities about 1 month after surgery.

Notes

Preparing for Spine Surgery

How do I help my child prepare for surgery?

It is important for you to help prepare your child or teen for surgery. This can:

- Calm your child's fears.
- Allow for easier and faster recovery.
- Calm you as you focus on your child.
- Help them understand what to expect and what will happen after.

Below are some common fears your child may have about surgery. They may fear:

- Being away from school and friends.
- Changes to their body. This includes 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 medicine.
- How surgery might affect what they can do in the future.
- Pain.
- Risks of surgery.
- Waking up during surgery or not waking up after surgery.
- Death.

What should I talk to my child about?

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

- Sit down with your family and make a game plan as soon as you and your child decide to have surgery.
- Give your child as much control as possible. Allow them to make choices when possible.
- Have your child make a list of questions to ask the care team.
- Talk about fears. Be honest about their fears. Children need truthful information to build trust.
- Tell your child that other children have had the same type of surgery.
- Make a plan for distraction tools, visits from friends and comfortable PJs.
- Offer praise, positive comments and support.
- Talk with your child and the care team often. This helps everyone feel more at ease.

- Tell your child it is OK to be afraid and cry. It can help them to know that you have similar worries.
- Tell your child that you are close by during their surgery and will see them as soon as they get back to their room.

Take care of yourself

- It is important for you to know what to expect before, during and after surgery. This can help reduce your fears.
- Make sure you, your child and your family are well rested.
- Take care of yourself. Make sure you are eating and resting well. Your child can sense and react to your stress level.

What happens before surgery?

Follow the doctor's instructions to get your child ready for surgery. They may need:

- A pre-op (before surgery) visit to meet with members of their care team. This includes:
    - The anesthesia team. They ask questions about your child's medical history.
    - A child life specialist. They talk with your child about surgery and give a tour of the area.
- Blood or labs checked.
- CT scans or MRI.
- X-rays.
- A pre-op visit with their doctor or with a nutritionist to talk about nutrition concerns. This could include concerns about your child:
    - Being overweight or underweight.
    - Recent weight loss or weight gain.
    - Eating habits.
- You can find a pre-op checklist in the Resources section of this handbook on page 56.

Note to parents: If your child is fed through an NG or g-tube, talk with the doctor or nutritionist. They will assess if it is enough to prepare your child for surgery.

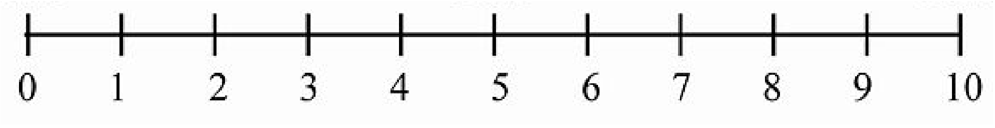
One month before surgery

- Your child should focus on foods with iron and protein for 1 month before surgery. This includes foods like meats, nuts, eggs and green, leafy vegetables. Ask your child's doctor if they need a multivitamin with iron.

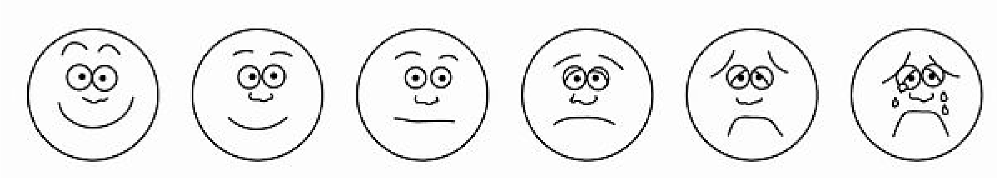
One to 2 days before surgery

- Your child's doctor may advise they take an over-the-counter laxative like MiraLAX. This can help prevent constipation (hard bowel movements) after surgery.
- Your child should drink lots of fluids, so their body is well hydrated. This will also help prevent constipation.
- Pack your child's bag. You will find a 'What to Bring' handout in the Resources section of this handbook on page 56. Other families have said the following are helpful:
  - A robe or loose-fitting shorts and T-shirts.
  - A tablet, books or activities.
  - Their favorite snacks.
- Wash your child's hair and put it in a metal free band if it is long.
- Your child should bathe or take a shower the night before surgery.
  - It is important to wash really well under the arms and the groin area.
  - Your child's skin should be wiped with the CHG cloths 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 56.
- Your child should not take a shower or eat the morning of surgery.
- Your child should not wear contact lenses, makeup, jewelry or nail polish to the hospital on the day of surgery.
- Review the pain scale your child will use after surgery.

On a scale of 0 to 10, with '0' being no pain and '10' being the worst pain you can imagine, what number are you feeling 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

What to Expect in the Hospital

Your child's plan for recovery

Idiopathic spinal fusion

Recovery for: _______________________________________

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 CHG cloths to wash your child's back.
- Take your child to the operating room (OR) for surgery.

After surgery

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

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

Most patients are discharged 1 to 3 days after surgery.

Please read the following sections to learn more about your child's care for spinal fusion. This plan for recovery can give you information about what to expect during your child's hospital stay. The exact 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. Most patients go home on day 2 after surgery. Some children stay more or less days depending on how they are doing. This is not related to the success of the surgery.

Day of surgery	
Diet	• May be allowed ice chips, clear liquids and solid foods when ready
Activity	• Use the incentive spirometer 10 times an hour when awake to help keep the lungs healthy • May log-roll, or turn, every 4 hours with help from staff • May move from bed to chair with help from staff • Physical therapist (PT) will see your child
Medicines	• Through the intravenous (I.V.) line: - Fluids - Antibiotics to help prevent infections for about 24 hours - Pain medicine - Medicine for an upset stomach if needed
Pain management	**Pain management goals after surgery:** • Rest • Sleep • Participate in turning in bed • Deep breathing **Pain management plan:** • Valium through the I.V. line for tight muscles (spasticity) as needed • Pain medicine with a patient-controlled analgesia (PCA) pump • Extra I.V. pain medicine if the PCA pump is not enough • Body position for comfort • Relaxation techniques • Use the relaxations skills to help relax • Use the comfort measures you learned about, such as pillow positioning and music **When to talk to the team about pain:** • Tell your child’s nurse if their pain is not better or they have muscle spasms. • Tell your nurse if they are itchy. • Tell your nurse if their stomach is upset or hurts.

Other care	- Your child's care team will check vital signs and do an assessment about every 4 hours
	- Tell your nurse if your child has:
	  - Numbness or tingling in the arms or legs
	  - Decreased feeling in the arms or legs
	  - Surgery bandage soaked with blood
	- A Hemovac drain will collect fluid from the surgery wound if needed
	- Oxygen if needed
	- Pulse oximeter (pulse ox) to check oxygen levels
	- Foley catheter to drain urine

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.

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 • Physical therapy if they did not see your child on day of surgery • Move from bed to chair several times with help from staff • Start walking with staff and family • You may help your child move around
Medicines	• Through the I.V. line: - Fluids may stop if your child is drinking liquids - Medicine for an upset stomach if needed • Medicine for constipation if needed
Pain management	**Pain management goals:** • Get out of bed at least 3 times • Physical therapy session • Occupational therapy session • Turn in bed • Deep breathing • Rest and sleep **Pain management plan:** • Stop PCA pump • Pain medicine to swallow every 4 hours • Begin anti-inflammatory medicines like ibuprofen (Motrin or Advil) • Valium for tight muscles as needed • I.V. pain medicine if needed for severe pain • Schedule PT visits with pain medicine • Body position for comfort • Support relaxation techniques **When to talk to your child's team about pain:** • Tell your nurse if your child's pain is not better or they have muscle spasms. • Tell your nurse if their stomach is upset or hurts. • Move your child in their bed using a log-roll technique.

	• Help your child get out of bed. • Allow your child to rest between therapy visits. • Use relaxation skills to help rest. • Use comfort measures, such as pillow positioning and music.
Other care	• Your child's care team checks 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 - Surgery bandage soaked with blood • Pulse oximeter (pulse ox) to check blood oxygen level if they still have PCA pump • Foley catheter may come out • Blood work (labs) if needed • Fever is common 1 to 2 days after surgery. The care team may give your child acetaminophen. **NOTE:** Teen girls may start their menstrual cycle (period) after the surgery.

Post-operative day 2 and 3 (day of discharge)	
Diet	• Regular diet
Activity	• Walk at least 3 times a day around unit • Start practicing stair steps • Out of bed with help from family
Medicines	• Stop I.V. fluids • I.V. will stay in place until discharge • Pain medicines to swallow • Medicine for constipation if needed
Pain management	**Pain management goals:** • Get out of bed at least 3 times and walk • Bath and activities of daily living (ADLs) like getting dressed • Physical therapy session including stairs • Occupational therapy session • Continue turning in bed • Deep breathing • Rest and sleep **Pain management plan:** • Pain medicine to swallow every 4 hours as needed • Valium to swallow for muscle tightness as needed • I.V. pain medicine if needed for severe pain • Continue anti-inflammatory medicine • Position their body for comfort • Use relaxation techniques **When to talk to the team about pain:**

	• **While pain medicines are not scheduled, you should ask for them before pain is severe.** • Ask for pain medicine before an activity if your child has pain. • Tell your nurse if the pain is not relieved or if your child has muscle spasms. • Tell your nurse if their stomach is upset or hurts.
Other care	• Your child’s care team checks 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/JP 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 ADLs

Notes

After Surgery: In the Hospital

Your child will go to the PACU (post anesthesia care unit or recovery room). Our staff will move them to a patient care area when they are ready. Your child may look pale and have a puffy face for 1 or 2 days. This is normal after surgery. It is because of the way your child was positioned during surgery. Your child may go to the intensive care unit (ICU) if their doctor thinks they need to have special care overnight. Our team will check on them through the night.

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

Monitors and machines

- Your child may need oxygen when they wake up. A machine called a pulse oximeter will check their oxygen level. A wire connects the machine to a sticker on your child's finger.
- 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.
- The nurses and techs will check your child's temperature, heart rate, blood pressure and breathing during the day and at night.
- The nurses will also check the feeling and movement of your child's legs and feet during the day and night. This tells us if the nerves and blood vessels in their legs are working. Tell your nurse or doctor about any changes in movement or feeling.

Drains, tubes and I.V.s

Your child will have 1 or 2 **intravenous** catheters called I.V.s. They will get an antibiotic through their I.V. They will also get fluids through their I.V. until they can eat and drink.

- When your child can drink well, the I.V. fluids may be turned off.
- The I.V. will stay in place until your child is ready to go home.

A small, soft tube called a **Foley catheter** is placed during surgery. It drains urine from your child's bladder. The tube goes into the urethra, the opening in the body where your child urinates.

- A bag connects to the Foley catheter and collects urine. The nurses and techs will empty the bag 2 to 3 times a day. This helps your care team keep track of your child's fluid levels.
- The Foley is removed the morning after surgery. The nurse or tech will help your child get up to the bathroom.

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

Pain management

Pain management is an important part of your child's recovery. 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 and if there is anything you know works well for your child.

- Our staff will check your child's pain with a pain scale.
- The pain scale includes a rating from 0 to 10. Zero is no pain. Ten is the worst possible pain. Our goal is to lower the pain as much as possible.

There is more information about pain in the Pain After Surgery section on page 47.

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

Pain makes it hard to move, walk and take a deep breath. Pain management allows your child to engage in activities for their recovery. A PCA pump is a good way to manage pain right after surgery.

The PCA pump is a machine that gives pain medicine (analgesia) to your child. The pump controls a syringe that has the pain medicine your child's doctor orders.

How does it work?

- Your child pushes a button on the pump when they have pain. The pump then gives the pain medicine to them through their I.V.
- The medicine goes into your child's vein through their I.V. catheter and into their bloodstream when they push the button.
- They can also use it before an activity that might cause pain.
- A PCA pump allows your child to decide when to get pain medicine. They are the only ones who should press the button unless their doctors tell you something different.

- The pump is programmed so they cannot get too much medicine.
- Your child’s doctor can tell how much pain medicine your child needs to stay comfortable. The doctor can make changes when needed.

Why should my child use a PCA pump?

- Some children are afraid to ask for pain medicine. Some children feel that pain medicine is worse than the pain itself.
- A PCA pump is already connected to an I.V., so the nurse does not have to give anything extra through their I.V.
- The pump works well for children because they are not afraid to say that they have pain.
- Please tell your child’s nurse right away if you think your child’s pain is not being well controlled.

How safe is the PCA pump?

- The pump is programmed to only give your child a certain amount of medicine.
- The pump has a lockout time that prevents your child from getting too much medicine. Even if your child pushes the button, medicine is only delivered if the lockout time has passed.
- Your child’s nurse and providers watch 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, red face
- Feeling too sleepy or like it 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.

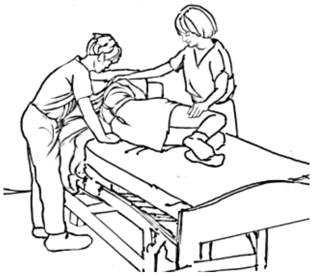
When your child can eat and drink, the nurse will turn off the PCA pump. Your nurse can give your child pain medicine through their I.V. if they do not have a PCA pump. Your child can take pain medicine such as a liquid or pill to swallow.

Other things to help your child's pain include:

- Tell us what has helped in the past.
- Have them take deep and slow breaths.
- Distract them with videos or TV.
- Play music.
- Help them imagine they are in their favorite place.
- Ask your nurse to call the child life specialist for more tips to help reduce pain.

Moving after a spinal fusion

- **Physical therapy** starts after surgery. A physical therapist will teach you and your child the safest way for them to move.
- Your child can take pain medicine before or after therapy sessions to help with pain.
- Moving and turning in the right way can help your child heal, get stronger and have less pain.



- It is 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 you and your nurse can help. Your child will be able to change positions themselves as the soreness improves.

Turning in bed

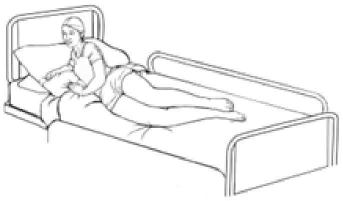
Keep your child's body and back in a straight line, like a log, when you turn them in bed. A physical therapist and nurse will teach you how to roll your child in one movement. This is called a log-roll. As your child feels better, they can help.

- Roll so that their hips, knees and shoulders stay in line and move together. Do this every time you change your child's position in bed.
- Avoid any twisting and bending movements.
- Place pillows between your child's knees and behind their back when they are laying on their side. You can also place a pillow under their top arm.
- Place pillows under their knees and arms when your child is lying on their back.

How to sit on the side of the bed

A physical therapist will teach you a safe way to sit your child up. You can also follow these steps to help them sit up on the side of their bed:

- Keep your child's back straight.
- Bring their knees up so that their feet are on the bed.
- Log-roll them onto their side.
- Your child should push against the mattress with their elbow and their hand.
- Your child pushes up with their arms at the same time that you lower their feet.



How to get out of bed

Your child's physical therapist will teach you how to safely get your child out of bed and walk the morning after surgery. The therapist and your nurse may ask your child to sit in a chair for at least 45 or 60 minutes 3 times a day after surgery. The physical therapist, your nurse and you can help your child get out of bed and walk at least 3 times a day.

Daily activities

Your child should:

- Sit in a chair for at least 45 to 60 minutes. Do this at least 3 times a day starting the day after surgery.
- Walk in the hallways at least 3 times a day with help.
- Start moving as soon as possible. Children who move sooner recover faster. It will be hard to get your child up the first time, but it will help lower their risk of problems.
- Each day your child should move around more than they did the day before.
- Your child's physical therapist will teach you how to help your child with mobility and exercises. The physical therapist will help your child practice going up and down stairs if you have them at home.

How to protect your child's lungs

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

- Your nurse or respiratory therapist will teach your child how to use it. This will help prevent pneumonia and other lung problems.
- Your child should hug a pillow when they cough to put less stress on their back.
- Many children have a low-grade fever after surgery. Using the incentive spirometer can help the temperature return to normal.

Feelings

It is normal for your child to go through mood swings in the hospital. They may be withdrawn and not want to talk or answer questions. They may want to be alone. These are normal feelings.

Some tips to help work through the feelings include:
- Help your child stay connected with their friends.
- Make time for visits, phone calls and their usual social connections.
- Remind your child of what they did today that they could not do the day before. Stay positive and aware of their progress.
- Be patient and understand your child may not feel like themself.
- Ask friends to send cards or letters during the hospital stay or healing time at home.

Your child's feelings and mood will improve as they feel better and can-do normal activity again. Try a sponge bath and do their hair when they can sit in a chair and walk to the bathroom.

Teen girls' menstrual cycles (periods) are often irregular after surgery. Their cycle should return to normal in 1 or 2 months.

Eating and drinking

Your child may only be allowed to have a small amount of ice chips or sips of clear liquids right after surgery. The doctor will change the diet order as your child is able to eat and drink more.

Helpful tips

- Pack gum in your suitcase if your child likes gum. Chewing gum after surgery may help your child's bowel function return to normal more quickly.
- Tell your child's nurse if they feel nauseated or like they are going to throw up (vomit). They can give your child medicine to help.
- Your child can take pain medicine by mouth when they can eat and drink.

- Constipation, or trouble having a bowel movement (BM), is normal after surgery. The pain medicine and decreased activity cause constipation. Your child should drink plenty of fluids and move around as much as possible.
- Tell your nurse if your child has problems eating or drinking. Your nurse can call a nutritionist to talk with you and your child. Your child needs fluids, protein and vitamins to heal.
- If your child gets tube feeds, it is best to restart them as quickly as possible. The feeds may be changed by the nutritionist to allow for better and quicker healing.

Preparing to go home

Occupational therapy (OT) can help your child be more independent. Your therapists will see you after surgery. They can help your child:

- Learn how to bathe, get dressed and go to the bathroom. The therapist calls these things ADLs or activities of daily living.
- Try new ways of doing things that can help them be safe.
- Practice ADLs.

Getting dressed

Your child should:

- Bend at the knee to lift their legs and feet when they put on pants, socks and shoes. Do not bend over at the waist to reach your legs and feet.
- Keep their back straight when they put on button-up shirts and coats. Do not twist at the waist.
- Sit in a chair and bend their leg at the knee and place their foot on their other leg when they tie their shoes. They should not bend down at the hips.

Brushing teeth

Your child should:

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

Using the bathroom

Your child should:

- Bend at the knees to sit down and stand up from the toilet. Getting up and down from the toilet can be hard. Someone should help your child at first.

- Face forward when they wipe themselves after going to the bathroom. They should not twist or bend at the waist.

Getting around at home

Your child should:

- Pick things up by bending at their knees, not their hips.
- Be able to reach their things in their bedroom, bathroom and kitchen. They should not have to reach high or bend down to get their things.
- 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.

To get ready for OT:

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

Notes

After Surgery: At Home

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

Care of the incision

Keep your child's incision clean and dry. It is important to help prevent 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 you go home, your doctor will tell you how and when to change it.
- There may be Steri-Strips or a clear mesh tape over the incision. This tape should remain over the incision and will often fall off on their own in 2 to 3 weeks. You can trim the edges of the tape if needed. Clean your scissors with alcohol before you use them to trim the tape.
- Stitches are often on the inside. This means the doctor does not need to remove them.
- Your child's skin may look a purplish color if the doctor used skin glue.
- Put clean clothes on your child and change the bed sheets if they get dirty or wet from body fluids until the incision heals.

Pain control

Your child may need pain medicine during the first 1 to 2 weeks at home. Your doctor will give you a prescription. Your child should be able to slowly stop taking it over 1 to 2 weeks.

- Your doctor will let you know if you can give over the counter medication such as Ibuprofen.
- Change your child's position often so they do not get sore from staying still too long. Walking often will help with soreness.
- Your child may still feel tired for 3 to 4 weeks after surgery. This is normal.
- Encourage your child to do things they enjoy like TV, music, reading or games with friends. This helps distract them from the discomfort.

See the Pain After Surgery section on page 47 for more information on managing pain.

Activities of daily living

Hair

You can wash your child's hair as often as you want. There are ways to do it until your child can shower.

- If the bathroom sink is short enough, place a chair in front of the sink. Sit your child facing away from the sink and tilt their head back (like when you have your hair washed in a salon).
- Place a chair with the back against the kitchen sink. Your child should kneel on the chair facing the sink with the front of their thighs pressed against the back of the chair. Tilt their head forward and use the sprayer hose. Make sure that your child keeps their back straight to protect it.

Taking a shower

Keep the incision clean and dry until the doctor tells you that your child can shower. Help your child take a sponge bath until they can shower. This helps to keep water away from the incision.

When your child can shower, pat the incision dry with a clean towel.

- Your child may feel dizzy or faint when they shower. To help with this:
  - You should be close by the first few times they shower.
  - Put a waterproof chair in the shower for your child to sit down during the shower.
  - Use warm, not hot, water.
- Use a mild soap around the incision.
- Your 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 you did in the hospital. Your child should take rest breaks during the day. Increase their activity and have them walk more each day.

Eating

The goal is for your child to not lose more than 10 percent of their body weight. Eating a well-balanced diet and drinking enough fluids can help to:

- Heal quicker.
- Maintain weight.
- Regain strength.

A balanced diet means that your child eats meals that include 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.
- Get extra calories and protein by drinking a nutritional supplement like Ensure or Boost. Ask your doctor or nutritionist about these.

- 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.

Your child should eat 5 or 6 small meals a day, so they do not feel too full. This can help them get all the calories and nutrients their body needs.

If your child got tube feedings before surgery, they should continue them at home. Talk with your care team about changes to the feeds if needed. They may increase calories and protein for healing.

School

Your child's doctor will tell you when they can go back to school. This is often 2 to 3 weeks after surgery. The care team can give you paperwork that allows your child to do their schoolwork at home. Your child can start with half days of school their first week back.

School books are heavy to carry. You can ask your child's school to:

- 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.

Physical activity

Your doctor will tell you:

- When your child can drive. They should always wear their seatbelt.
- When your child can go to physical education (PE) classes. Tell the doctor what sports your child does so they tell you when they can start again. Your child may be able to begin some light exercise, such as swimming, in 2 to 3 months.
- Your child should not lift anything over 10 pounds until your doctor says it is OK.
- Your child should not swim in lakes, oceans, streams and rivers 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 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 your child needs to pick up something off the floor. Do not bend or twist at the waist.

When to call your surgeon

You should call your child’s surgeon if they have:

- A temperature of 101°F or higher without cold, flu or other illness.
- Increased redness, swelling, tenderness, pain or warmth at the incision.
- Drainage or bad smell at the incision.
- Open skin or wounds near the incision.
- Pain that does not get better with pain medicine.
- Numbness or tingling in your child’s arms, legs or feet.
- Change in bowel or bladder control.
- Vomiting (throwing up).
- Any questions or concerns about how your child looks or feels.

Notes

Pain After Surgery

Pain management

Pain control is very important. The doctors and staff will work with you and your child to help prevent or decrease their pain and discomfort when possible. Some discomfort is normal after spinal fusion surgery. We will use several ways to help control the pain. This includes medicines, activity, rest, body positioning and diet.

Our goal is to ensure your child has enough pain control to sleep, walk and turn in bed. Please tell your nurse if your child's pain is not controlled well enough for them to do these things.

Your child has the right to:

- Receive care that will decrease or prevent discomfort.
- Be told the truth about their discomfort.
- Tell us if they have pain and what they think will help make it better.
- Cry or object when anything hurts or upsets them.
- Get answers in a way they can understand.
- Get painful treatments in a place outside of their room.
- Watch a procedure if they want to; like a dressing change or an I.V. placement.
- Be with their parent or caregiver when they have pain.

How can I help my child?

You are an important part of your child's treatment, including pain management. Here is how you can 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 pain and what options you have.
- Tell us what has helped your child's pain in the past.
- 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.
- Ask questions.

We learn about your child’s pain by:

- Listening to what your child says.
- Watching what your child does.
- Noting changes in their vital signs.
- Talking with you about what you see.

How do you measure pain?

We use different pain scales to measure pain. Please review page 23. Your child is the best person to tell us about their pain. They are the expert on their pain. Please ask your nurse to show you the tool we use for your child.

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

- Crying or fussing.
- Holding, touching, protecting 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 you do to help?

Medicines

There are many medicines that help decrease pain. The medicines are given through an I.V. or for your child to swallow. Your child’s doctor will talk with you about the medicine that is best for your child. Tell your nurse or doctor if you have concerns or questions about your child’s pain medicines.

Play and relaxation

Our staff is trained to use play, distraction and relaxation with children. Here are some ideas you can try:

Babies

- Rocking or holding

- Breastfeeding or using sucrose during painful procedures
- Swaddling
- Skin to skin contact or kangaroo care
- Singing or music
- Talking to them softly
- Gentle massage
- Pacifier
- Favorite toy
- Low light in the room

Toddlers and preschool-age children

- Rocking or holding
- Singing or music
- Reading books
- Watching movies or TV
- Blowing bubbles
- Playing with toys

School-age children and teens

- Talking about what helped in the past
- Telling them what to expect and make a plan for difficult situations
- Deep and slow breathing
- Watching movies or TV
- Playing video games or listening to music
- Imagining they are in their favorite place
- Visits with friends
- Massage

Review 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 we can do to help decrease your child’s pain.

Notes

Inpatient Rehabilitation

Your child may go to the Children's comprehensive inpatient rehabilitation unit (CIRU) if their doctor wants them to stay at the hospital for therapy after surgery. The CIRU staff includes pediatric-trained physiatrist or rehabilitation doctor, nurses, techs and case managers. They will:

- Support you, your child and your family during your 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. Talk with our social worker or chaplain about support groups. Connect with other 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, doctors, therapists, nurses and others. The purpose of the meeting is to:

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

Your case manager or social worker will tell you when your child's first team meeting is. Make plans to go to the first meeting. Each patient has 5 to 10 minutes to talk to the team. Your CIRU case manager can give you an update if you cannot go to a meeting. You only go to the first meeting unless you ask to go to another meeting. Your child's case manager updates you after every team meeting.

Some parents feel uncomfortable asking questions at the team meeting. You can ask your case manager if you would rather meet with a smaller group. We want you to feel comfortable talking with the team. Ask your nurse or therapist if you have questions about your child's team meeting or treatment plan.

Your child’s rehab schedule

The rehab team will create a program to meet your child’s needs. Some of your child’s activities are the same as other patients’, while others may be different.

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

A sample schedule is listed here:

7 a.m. to 8:30 a.m.	ADLs, medicines and tube feedings (if needed)
8 a.m. to 8:30 a.m.	Breakfast
8:30 a.m. 12 p.m.	Individual or group therapy sessions
12 p.m. to 1 p.m.	Lunch group or break time in your child’s room
1 p.m. to 4 p.m.	Individual or group therapy sessions
4 p.m. to 5 p.m.	Group time or break time in your child’s room
5 p.m. to 6 p.m.	Dinner in your child’s room
6 p.m. to 8 p.m.	Family time and evening programs
10 p.m.	Lights out

Therapy sessions may include:

- ADLs, such as washing, dressing and brushing teeth.
- Transfers into and out of bed.
- Transport to and from room when needed.
- Diaper changing or bathroom visits.
- Caregiver training.
- Your child also may take part in activities, such as:
    - Exercises
    - Cooking
    - Study time
    - Pet therapy
    - Community outings
    - Craft and peer groups

You will get your child’s schedule in the evening before the next day. Your child should be ready for their first therapy session. Take them to the assigned area. We want them to get their full treatment time. Parents can join therapies. Ask your child’s team how you can participate.

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. Schedules may change because of:

- Special tests or procedures
- Visits from doctors
- Nursing care or medicine schedules
- Patient symptoms
- Therapeutic leaves of absence (TLOA)
- Special events

Sometimes, more therapy does not equal better therapy. Your child's energy level may be lower than normal because of the surgery or their long hospital stay. The rehab team may suggest rest breaks for your child. This can help them gain the most from therapy sessions.

Weekend schedules

Your child will have therapy on weekends and holidays. Weekends often include:

- A later start, which allows you and your child to sleep in.
- Change to group or individual therapy sessions.
- Special events and activities like:
    - Pet therapy visits every other weekend.
    - Chapel services on Sundays.
    - Movies on Saturdays.

Evening programs

All hospital patients are invited to take part in evening activities. 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.

- The Day Rehab program offers a full day program of physical, occupational and speech-language therapy. It includes school, nursing, case management and social work services.
    - The therapy day is like a child's school day. 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.

- The Outpatient Rehabilitation program includes 9 locations around Atlanta to help your child continue therapy.
- The Sports Medicine program includes 12 locations around Atlanta to help your athlete return to sports after spine surgery.

Rehabilitation doctor follow-up

Your child may be scheduled for follow-up visits at the Children’s rehab clinic. This is often 6 to 8 weeks after discharge from the hospital. Your child will be seen by their doctor. They will talk with you about further treatment.

Notes

Resources

Pre-surgery checklist

One month before surgery

- Talk with your child's school about the plans for surgery and needed paperwork for home learning.
- A care coordinator:
  - Schedules a visit for your child 2 weeks before surgery.
  - Schedules a CT scan or MRI if needed.
  - Schedules a visit with the Anesthesia team and our child life team before surgery.

Before surgery

- A visit with your doctor
- A CT scan or MRI if needed
- A visit with the Anesthesia team
- A hospital tour and visit with a child life specialist
- Wash your child's bedding to include sheets and bed spread
- Pack your bags. You can find a list of what to bring on the next page.
- Do not let your child eat or drink after midnight the night before surgery.
- Use the chlorhexidine (CHG) wash as taught by the care team.
- Please call if you have questions about preparing for surgery.

What to bring

We want you to be as comfortable as possible during your stay. Here is a checklist of items you might want to pack:

- Comfortable, loose clothing, PJs, socks and underwear
- Bathrobe*
- Extra underwear
- Comfortable shoes or slippers
  - Favorite pillow*

- Favorite blanket*
- Laptop or iPad
- Music or white noise machine
- Toothbrush and toothpaste
- Mouthwash
- Hair care products
- Skin care products
- Deodorant
- Feminine supplies
- Snacks and gum

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

Traveling families and visitors

Below are area hotels that offer special hospital rates to patients' families at Arthur M. Blank Hospital.

- **Courtyard by Marriott, 1236 Executive Park Drive - 404-728-0708**
- Emory Inn, 1641 Clifton Road - 404-712-6700
- 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
- University Inn, 1767 North Decatur Road - 404-634-7327

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

- Home2 Suites, Perimeter Center, 6110 Peachtree Dunwoody Road – 770-828-0330
- The Westin Atlanta Perimeter North, 7 Concourse Parkway- 770-395-3900

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

- Arthur M. Blank Hospital: 404-785-6250 or dial 5-6250 from a hospital phone
- Scottish Rite Hospital: 404-785-2010 or dial 5-2010 from a hospital phone

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

Parking passes

Parking at Scottish Rite Hospital and Arthur M. Blank Hospital is free.

Family library

The library offers:

- Medical and health information for patients and families.
- Library staff to help you.
- Access to the Internet, e-mail and medical databases.
- Books and DVDs that you can check out

Arthur M. Blank Hospital Family Resource Library

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

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

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

Making needles hurt less

You play an important role for your child during painful procedures. You and your care team can work together to help your child cope with needle sticks.

Prepare	• Use simple words to tell your child what is going to happen in a way they can understand.
Use soft language	• Avoid 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 promises you cannot keep, such as, "I promise it will not hurt." • Children need truthful information to build trust in you and others.
Share	• Tell the care team what helped or did not help your child in the past. • Young children can see pain as a form of punishment. Tell your child it is not their fault that they are going through something painful. • 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 numbing cream before needle sticks. • You can ask for the needle sticks to happen in a treatment room if one is available. This allows your child's room and bed to be a peaceful space.
Offer choices	• Offer your child choices before and during the procedure. This gives them a sense of control. 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 stay calm. Your child may become more scared if you are upset. • It is OK to ask for help or leave the room if you are not able to support your child through a painful procedure.
Comfort	• Hold your child's hand or hold them in a comforting position if possible. Ask your care team how you can best do this.
Praise	• When giving praise, avoid saying "good boy" or "good girl." Your child might think they are only good when they do not cry or move. • Tell your child when they do positive behaviors such as, "You did such a great job holding still," or,"I like the way you let us know how that felt!"

Support	• Tell your child that crying or being mad is OK. Sometimes crying or expressing emotions helps a child get through painful events.
Offer ideas	• Talk with your child about ways to help them through a painful procedure: - **Breathe** with deep and slow breaths. Try blowing bubbles. - **Squeeze** someone's hand if they feel pain. - **Count** before or during the needle stick. - **Look** at something like a book, a light up toy or a video. - **Imagine** their favorite place or doing something they like. - **Listen** to their favorite music or sing a favorite song. - **Talk** about something they like. - **Encourage** them to hold still during the needle stick.

Chlorhexidine (CHG) cloths

What are CHG cloths?

CHG is a special kind of skin cleaner. We will provide the cloths to you at your visit before surgery.

- You will use it at home to wash your child's skin the night before surgery (pre-op).
- You should not use it if your child is younger than 2 months old.

Why does my child need CHG wipes before surgery?

CHG removes more germs from the skin than regular soap and water. CHG helps prevent infection during and after surgery.

Your child should not use CHG if:

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

How do I use the CHG cloths?

Use CHG cloths to wash your child's skin **the night before** you come to the hospital. Our staff will help wash their skin again just before surgery. Follow these guidelines at home:

Before you use the CHG cloths:

1. Remove all jewelry, such as earrings, necklaces and bracelets. Keep them off until after the surgery. Talk with your nurse if there are religious or cultural reasons to leave jewelry on.
2. Clean and trim your fingernails and toenails to help decrease germs. Take off any nail polish.
3. Wash your child's skin with regular soap and water first. Rinse and dry their skin with a clean towel.
4. Do not put on lotions or makeup after their shower or bath. These products may attract germs 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 touch these areas, rinse them well with clean, warm water to prevent irritation.

To use the CHG cloths:

1. Use the CHG cloths to wipe the skin (see table on next page). Follow the table below for instructions.
2. Do not rinse the area with water unless a rash or redness happens.
3. Let their 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 the CHG cloths:

1. Do not flush the cloths down the toilet. Throw them away in the trash.
2. Put your child in clean PJs.
3. Make sure your child's bed sheets and blankets 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 give your child a bath or shower the morning of surgery.
6. Our staff will wash your child's skin right before surgery. We will also put your child in a clean hospital gown and surgical hat.

Educational videos on-demand

You will have access to educational videos in your hospital room. The videos can teach you to care for your child. All of the videos are free.

You can watch videos about:

- Baby and child care.
- Child safety and CPR.
- Care for your child in the hospital and at home, such as asthma, diabetes, cast care and surgery.

- Nutrition, bottle feeding and breastfeeding.
- Parenting topics, such as how to talk with your child.

There are videos for children and teens. Many videos are available in Spanish. Ask your child's nurse if you have questions.

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 Arthur M. Blank Hospital 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 the hospital phone.
- The Family Support Services office at Scottish Rite Hospital 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 table below.

For questions or concerns about:	Talk with:	Contact:
Insurance coverage	A financial counselor	Patient Registration
Medicaid applications	A Medicaid caseworker	Patient Registration
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 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 issues that impact the patient's health. This program can help with housing, education, denial of benefits and other issues. For more information, call 404-785-2005 or dial 5-2005 from a hospital phone.

Helpful websites

This list of websites may be helpful for more information about scoliosis and spine surgery.

Orthopedic-related sites

The Children's Orthopedics Program

choa.org/medical-services/orthopedics

American Academy of Orthopedic Surgery

aaos.org

American Physical Therapy Association

apta.org

The Pediatric Orthopedic Society of North America

posna.org

Scoliosis Research Society (SRS)

srs.org

Others

Children's Healthcare of Atlanta

choa.org

Centers for Medicare and Medicaid Services

cms.hhs.gov

Georgia PeachCare for Kids

choose.amerigroup.com

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 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.

Notes

Glossary

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

Anesthesia: Medicine that causes deep sleep during surgery.

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

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

CT scan: A machine takes pictures of the body like an X-ray. The pictures are cross-sectional images, like slices of the body.

Foley catheter: A small tube put through the urethra to drain urine from the bladder.

Hemovac: A drain put in the incision during surgery. It removes blood or other fluids that collect in this area.

Idiopathic: No known cause.

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

Incision: Where the skin is cut for surgery.

Intravenous (I.V.): In the vein. This is a plastic catheter put in the hand, foot or arm to give fluid and medicine. A needle is used to put the catheter in.

Kyphosis: A curve in the spine that causes a rounded back.

Magnetic resonance imaging (MRI): A machine uses large magnets and a computer to take pictures of the body.

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

Occupational therapy (OT): A type of therapy the helps improve activities of daily living (ADLs).

Orthopedic: The medical teams and surgery that focus on the body's bone and muscle system.

Pathology: The medical team that focuses on what causes a disease and what happens to the body during a disease.

Patient controlled analgesia (PCA) pump: A device used to give pain medicine continuously and as needed. It gives a child control over their own pain management.

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

Scoliosis: A sideways curve of the spine.

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

X-ray: A machine takes pictures of the inside of the body made with special radioactive rays.

Notes

This handbook 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.

Health-related information changes frequently, and therefore information contained in this handbook may be outdated, incomplete or incorrect. This handbook may contain printed material that has been updated by Children's Healthcare of Atlanta. Please talk with a member of your child's healthcare team if you need an up-to-date copy.

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