

The Infantile Scoliosis Outreach Program

Growing Hardware/rod Parent Handbook

November 10, 2014

Introduction

This handbook is a compilation of personal experiences and stories from several ISOP constituent parents whose children underwent various typed of distraction rod, implant surgeries. Because we all wished that we'd been armed with some of this information before our children's surgeries, we want to share what we know with prospective growing rod hardware with patients and families. We recognize that, because each child's scoliosis is different, each family will experience the treatment process differently. Our hope is that, by reading this, you will have a better idea about what might occur and be better prepared for the surgery and settling into everyday life afterwards.

Please know that this document is provided to share our stories and experiences only, and must not, under any circumstances, be interpreted as medical advice or consultation. Please speak to your child's physician(s) about any medical questions or concerns you may have, and to get expert advice from those who know your child's specific case.

Since growing rod hardware types vary in type and technique, parents and caregivers considering spine surgery of any kind must seek out, and apply for acceptance, to a hospital program through a surgeon trained to perform proper procedure(s). Only surgeons trained in specific spine hardware techniques will have the knowledge and skills necessary to determine whether growing rod hardware will benefit your child. Before seeking out the a growing rod procedure, do as much research as possible on your own. If your child has a diagnosis secondary to scoliosis or Thoracic Insufficiency Syndrome (TIS), it must also be taken into consideration. The surgeon you choose should demonstrate the ability to understand the driving mechanics of your child's scoliosis. He or she should also be able to explain to you the role the spine hardware will play in controlling the progression of your child's curve. Remember also, that while curve reduction is desirable and attained through the use of various growing rod

implants specific attention will be directed to giving your child's inhibited lungs more room to operate and grow.

What is spine distraction hardware or growing rods?

Complications and monitoring

Complications from growing rods of any kind are common. Complications include but are not limited to: post-operative pain, infection, skin breakthrough, device fracture or device drifting due to stress fatigue, bone erosion, and device removal. Post-operative pain is managed with medications. Typically, a post-operative temperature of 101° or more warrants a call to the doctor to rule out infection. Monitor the incision sites for drainage, redness, or swelling.

Pursuing growing rod surgery

Each hospital will have its own protocol for assessing and accepting patients for growing rod implant surgery. The evaluating physician will let you know what tests to have done prior to the evaluation. We have found it helpful to have the following documentation available to send to the orthopedic surgeon's office if you have it already on hand:

- Current AP and lateral spine x-rays,
- Current CT scan and/or current MRI,
- Other diagnostic test results that pertain to or affect your child's scoliosis,
- A copy of your child's medical and family history form.

Also, when referred by a pediatrician or other doctor, ask him/her to write a concise synopsis of your child's medical history and onset of scoliosis. Finally, know how to contact the orthopedic surgeon's nurse, and make an effort to develop a good working relationship with this person. Once you are accepted to the hospital's growing spine program, you will be communicating with him/her often over the course of the next several years.

Preparing for the hospital stay

If possible, visit the hospital in advance. Travelers from out of the area may want to acquaint themselves with their surroundings as part of the pre-op day. Many hospitals offer tours through their Social Workers, Child Life Specialists, or Volunteer Office. They often can provide information on hospital services available to families, such as language translation, parking, internet access, play rooms, movie and book libraries, special activities, and the Pet Pal program. Children expected to be in the hospital longer than two weeks may qualify for educational services to keep them caught up with schoolwork. These professionals may also offer pre-surgery classes to help your child become acquainted with some of the medical equipment they may see before and after surgery. Every child is different and will have varying levels of desire or need for specific information regarding the hospital stay. Make sure your questions and your child's questions are answered ahead of time. Kids often want to know what their limitations will be; whether they will be able to feel the metal inside of them, whether they will look different, etc.

During hospital stay

Most hospitals have a surgery waiting area where a volunteer will check you in. There you may receive hourly calls from the operating room (OR) nurse assigned to your child. The OR nurse generally communicates how your child is doing and how the surgery is progressing. Once your child is out of surgery they will transfer him/her to a recovery room. Children with ventilators may be taken to the Pediatric Intensive Care Unit (PICU). One parent may be allowed to sit with the child in recovery. The sedation used in surgery will often disorient your child, so having a parent there is reassuring. Ask in advance what types of IV lines or catheters might be used on your child so you can prepare yourself. Also, understand what types of monitors will be used. Not all of them will be used at all times, and will depend on your child's medical needs.

Your child will need daily help with personal care. Plan to help your child with eating, sitting up gradually, getting in and out of bed, toileting, dressing, and walking up and down the hall. Your child will also need emotional support and encouragement. Being away from home, having movement restricted by the monitor cords, and pain, can all be frustrating and frightening. How you respond to the hospital environment will have an impact on how your child responds. Accepting the short – term difficulties and focusing on the long – term benefits of surgery will help you all keep a positive

outlook. This recovery time is also a great opportunity to utilize the resources offered by the Volunteers Office and the Child Life Specialist's team. Many hospitals organize craft times, puppet shows, and other activities to keep children occupied while recovering from implant and expansion procedures.

Remember that you know your child best. As the parent it is your honor to advocate for your child's needs and to speak up on their behalf. Develop a working relationship with any professional treating your child. When you demonstrate your willingness to be a part of the treatment team, professionals usually respond by offering more technical information and educating you about your child's care.

Parents and caregivers should recognize that surgery of any kind is stressful, in some way, on **every** member of the family. We have found it helpful to have an extended support system of people mobilized to help meet our needs, and that people are very willing and want to help. All you have to do is ask. Here are some ways others can support you and make your experience easier:

- Allow someone you trust to sit with your child during recovery so you can take a break.
- Arrange for someone to care for a sibling, bring you a meal, or clean your house.
- Appoint a person to send emails or make phone calls to update everyone on how the surgery went and how your child is recovering.
- Have someone you can be totally honest with listen empathetically to your frustrations and fears.

Taking everything on by your self is overwhelming and exhausting. While staying in the hospital with your child, don't neglect your own comfort!

- Bring things to do while your child is sleeping
- Wear comfortable clothes
- Get as much rest as you can
- Eat healthy meals
- Leave the hospital occasionally for brief walks outdoors

By taking good care of yourself, you will be ready physically and emotionally when your child needs you to help them be brave and strong.

Some parents have found it helpful to keep a notebook to record everything about their hospital experience, from professionals' names, medications used, side effects that may occur and contact information from other families they meet, to how to get around an unfamiliar town. Expansion surgeries are usually six months apart, so notes like this can be an invaluable reference later on. Learning from each stay at the hospital makes subsequent stays increasingly easier.

Pre-op and the moments just before surgery

If you are traveling from out of state to the hospital, preliminary tests done at home may be required. For example, children with heart complications might need medical clearance for surgery from their cardiologist. It is often the parents' or caregivers' job to facilitate communication between the orthopedic surgeon and any other specialists your child sees. During the winter months it is common to have a RSV swab done prior to travel. Your surgeon's office will also send out a letter with detailed instructions on food and liquid restrictions for the day of surgery (see NPO in the glossary section). Request any literature they may have to help you prepare your child for surgery.

Once you arrive at the hospital, typically the day before surgery, they will perform additional preoperative testing (typically called "pre-op) which **may** include: x-rays, CT scan, RSV swab, and blood and urine samples, however not all hospitals perform all the same tests. At the hospital you can also expect to meet:

□□□□□ **Nurses** who will assess and record your child's current health and record any current medications your child takes. Surgical nurses, who will assist and monitor your child during the procedure, will introduce themselves immediately before surgery.

□□□□□ **Residents** will ask you to acquaint them with your child's health history. Most hospitals that perform spine rod implant surgeries are teaching hospitals and, therefore, residents often monitor your child in postoperative care. Write down their names so you are not surprised when they come to check your child's progress. They may also discuss pain management with you. Some hospitals have a Pain Management Team whose sole purpose is to discuss pain management for your child, and record the effectiveness or ineffectiveness of pain medicines on children.

□□□□□ **Anesthesiologists** will meet with you directly before surgery to discuss the types of medications to be used during surgery and their risks. Be sure to notify him/her of any previous complications with sedation medications and any

allergies your child has. You will also be asked when your child last had food and liquid.

□□□□□ **A Respiratory Therapist** will explain your child's need for Chest Percussion Therapy (CPT) after surgery. This therapy is used to prevent excess fluids from pooling in the lungs causing pneumonia. CPT may be prescribed as an ongoing maintenance therapy once you return home to increase lung health. Other breathing therapies such as Bi-Pap may also be discussed.

□□□□□ **A Physical Therapist** may want to do a pre-operative capability and strength test. If your child receives ongoing physical therapy or will potentially require physical therapy after surgery, a therapist may visit with you. □□□□□□□□

Your surgeon will outline the actual implantation process, possible complications, and intended effect on your child's chest cavity and scoliosis. Most surgeons will ask you if you understand in non-medical terminology what will happen during surgery.

Many hospitals will often give your child a liquid dose of Versed to relax them before surgery. Since Versed is an amnesiac medication, it is unlikely that your child will have any recollection of the moments before entering the surgery preparation room. Some hospitals will also allow one parent to accompany their child to the preparation room until she/he is asleep. Sleep is induced by inhaling sedation medication via facemask. The decision to allow a parent into the preparation room is usually made by anesthesiologist. If you wish to go with your child, stress to the anesthesiologist your ability to handle this situation and the benefit to your child's feelings of safety and comfort. Many families do this and make it a routine part of the surgery process so the child knows that their parent's face and voice will be the last thing they will see and hear before sleeping. Sedation used during surgery is also amnesiac. Your child should have no recollection of the surgical process and may express frustration or confusing at "losing time" during the operation.

Pain Management

Ensuring good pain management for your child plays a key role in recovery. Pain adds to frustration, burns energy, and decreased your child's desire to move around. Each

child will experience pain differently and to differing degrees. Many pain medications are available to help your child be comfortable; here is a short list of possibilities:

- Tylenol (acetaminophen)
- Motrin (ibuprofen)
- Tordol (motrin family)
- Lortab
- Fentanyl
- Morphine
- Versed (amnesiatic)

We found it was incredibly helpful to avoid pain medications that might have side effects of nausea or slow bowels. Internet search engines will display links to websites with information on specific medications. Colace and Miralax are commonly used for constipation. Reglan and Zantac are often used for nausea.

Moving your child

Be sure to consult with the surgeon, nurses, and possibly physical therapy staff on how exactly your child should begin to become mobile again. Keep in mind that your child will be very sore and move slowly.

Be sure the Physical Therapist or any other person moving your child is aware of what kind of spine hardware your child has. For example, common protocol for the majority of spinal procedures is to sit the patient upright a couple days after the implant procedure. While this standard protocol better suits a patient who has recently undergone a fusion or hardware that is attached to the spine, it may not work as well with hybrid rods attached to the iliac crest(s). Because the hybrid rods are attached to the iliac crests on the pelvic structure, and an upper set of ribs, and not the spine many patients experience great pressure near the attachment sites on the pelvic structure when being placed in upright position prematurely and abruptly. It is recommended that patients with hybrid devices attached to the iliac crest(s) sit up gradually.

Request that a wheelchair with an adjustable back be provided for your child, if possible. If your child has hardware attached to the pelvis, an adjustable wheelchair will give the option of gradually sitting in the upright position, when she/he is ready

and the body has had time to acclimate to the change in spine position and the presence of the metal at the pelvic anchoring points.

Standing and walking will progress gradually, as well. Although the effects of gravity are stronger in the standing position than sitting position, many children find standing easier in the beginning. As always, never lift your child from under the arms. Instead, lift your child by supporting them under the bottom or back of the knees. Have them hold onto your shoulders to steady themselves when lifting.

Discharge protocols

Before your child is discharged, the surgeon will most likely order x-rays taken in the standing position, and possibly a CT scan to check the placement of the spine implants. Your child may also be required to wait until all doses of antibiotics have been given. Usually the attending physician will want to see that your child has been out of bed and moving around, and that she/he is eating and drinking approximately normal amounts and toileting regularly.

Make sure to ask any questions that you or your child may have before leaving the hospital. If you are from out of town, advise your doctors about how you plan to travel home. Discuss any special precautions or needs for safe travel.

If you keep a medical portfolio on your child, request copies of reports and x-rays early so enough time is available to make them. X-rays may have to be requested directly from Radiology. Some doctors may prefer to mail them to you and require you to fill out a release of information form in the Medical Records office. A medical release of information form may also be necessary if you request that copies of surgical reports and other documentation be sent to your child's physicians and specialists at home. Be sure to provide current addresses to the surgeon's office.

Some surgery situations require that your child stay home from school and avoid contact with others for a specified period of time. This sometimes occurs during cold, flu and RSV season, so be sure to clarify this with the doctor. Also, be sure you fully understand the purpose of any medications prescribed, and their dosages. Finally, get names and phone numbers of professionals to contact in case complications or other questions arise at home.

Post-operative care at home

Be certain to follow the doctor's orders for pain management, cleaning of the incision, bathing, restriction of activity, and exposure to others. Monitor the incision closely and report any of the following: redness, swelling, drainage, and opening of incision. Also report if your child has a temperature greater than 101°. Watch closely for excessive pain, or for metal protruding from under the skin.

Preparing family members and friends

Family members and friends will be excited to see your child return home. Visible changes in height, posture and correction of curve are possible. Surely lots of hugs will be shared! You'll want to encourage everyone to hug above or below the attachment sites, and directly on. While most children say they do not feel the implants inside of them, once pressure is applied, the metal can be felt. This may make your child uneasy, or could cause pain.

Also, show family members and friends before and after x-rays, and educate them about your child's diagnosis and its treatment options. Knowing more details will help them understand why you have chosen this course of action for your child. Education will also equip them to share information about infantile scoliosis or other diagnoses with others around them.

Preparing to return to school

Your surgeon will inform you when it is safe for your child to resume school. Many parents have found it useful to meet with school staff and educate them about the spine hardware and any restrictions prescribed by your surgeon. A school nurse or social worker may want to draw up an Individual Health Plan (IHP) for your child or 504 Plan. An IHP or 504 Plan will record any limitations your child might have, especially regarding physical education class and recess. Also, special concessions may be made by the school for your child, such as frequent restroom breaks, a pillow for hard back chairs, and your child being last in line so his/her back doesn't get bumped. There may also be instructions for fire, earthquake and tornado drills.

Some parents have gone so far as to bring x-rays in to the school to show staff and students what the implants look like. By educating the people around your child, you help foster awareness regarding infantile, congenital, juvenile scoliosis.

Expansions

Remember that growing rods are meant to expand with your child to provide optimum expansion of the spine and chest cavity. Your doctor will determine how often your child's distraction hardware needs to be expanded. Most children receive expansions every 4–6 months based on their growth and the curve management needs. The pre-operative experience is much like the initial implantation surgery. The new magnetic spine hardware/rods eliminate the need for repeated surgical expansions, which reduces overall complication rates associated with standard growing rod types. Your surgeon will send you a letter explaining the day and time to arrive for pre-operative tests and meetings, as well as any food or liquid restrictions.

Surgical Expansions usually take an hour or less to perform. In most cases, the surgeon will make a 1–3 inch vertical incision directly over the attachment site. That being said, every child's spine is different, so surgical protocols depending on your child's specific case will vary. The pediatric spine surgeon will gauge the adjustment/growth needed to provide support to your child's spine and chest cavity. Again, your child will be taken to surgery recovery for monitoring and then moved to a regular room. Discharge protocols and post-operative care at home will be largely the same. Be sure to follow your doctor's directions, write down and don't hesitate to ask any questions you might have.

Continuous Monitoring At Home

The growing rod devices will function differently for each child based on the size, shape and nature of their scoliotic curve and/or chest cavity deformity. The devices will improve lung function for each child differently as well. Since the body functions as a whole, changes in the position of the spinal structure will also affect muscles in the neck, torso, arms, hips, and legs. It is important that parents continuously monitor their child's physical appearance and mobility. By this we mean, how your child sits, stands, walks, and their overall range of motion. This is especially vital in children with connective tissue disorders, or other disorders involving the muscles. Consult with your specialists and physicians regarding the benefits of an on-going physical therapy program at home. Discuss any chronic compensating postures or movements to your child's orthopedic surgeon.

Continuous monitoring also involves being aware of the appearance of your child's back. Remember, in some cases the metal is outwardly noticeable in children of slim

nature or slender phenotype. As with post-op, be alert for migration and unanchoring of the devices. Many parents also routinely note their child's weight. Taking serial photographs is an effective way to monitor your child's back. Some children with multiple medical issues have difficulty gaining and maintaining a healthy weight. Your orthopedic surgeon can tell you what a healthy weight is for your child in regards to the metal implants.

Self-Esteem

Take care that your methods of monitoring your child's health do not cause your child to fear complications, or have a negative view of their self-image. Most children heal remarkably fast after procedures and want to resume "life as usual". They want to be just like the other kids around them. Medical needs should function as a part, not the defining factor, of your child's life. Being involved in artistic, and social activities at school, and in the community gives your child the opportunity to find ways to excel and define themselves aside from their medical issues.

Commonly used terminology

CT/CAT Scan – Computed Tomography or Computed Axial Tomography – Images obtained that cannot be seen on a standard x-ray. Multiple images are taken and compiled by a computer to create complete, cross-sectional pictures (slices) of soft tissue, bone, and blood vessels. Used as an early diagnosis tool for many diseases.

MRI – Magnetic Resonance Imaging – a diagnostic device which uses a strong magnetic field to create images of the body's internal parts.

Chest Wall – In respiratory physiology, the total system of structures outside the lungs that move as a part of breathing; it includes the rib cage, diaphragm, abdominal wall, and abdominal contents.

Thoracic Insufficiency Syndrome – As a result of any number of diagnoses, the chest cavity lacks the ability to grow large enough to support normal breathing and lung growth.

Rib Fusion – A medical condition of the ribs where they are stuck together. Bone growth has occurred between ribs resulting in a solid mass, which inhibits expansion of the lungs.

Rib Hump – also called Rib Prominence, as the spine curves abnormally the involved vertebrae are forced to rotate. The curve of the spine and the displaced ribs become visibly noticeable.

Vertebral Anomalies – various congenital deformities of the bones that make up the spine.

Iliac Crest – The large, prominent portion of the pelvic bone at the belt line of the body.

Lines

Depending on your child’s individual circumstances, his/her surgery will require some of the following “lines”:

□□□□□□ **IV.** Your child will need one or more IV lines to distribute pain medicine, antibiotics and fluids. Some hospitals prescribe antibiotics post-operatively as a precaution.

□□□□□□ **Arterial line.** This line can be used to draw blood samples, and also measures blood pressure inside the arteries. It can be placed into the groin area. The readout from this line will show up on the child’s monitor.

□□□□□□ **Foley catheter.** This is a tube that collects urine directly from the child’s bladder into a bag hanging from the bedside. Doctors measure the urine output to keep track of fluid input and output and to measure kidney function.

□□□□□□ **Chest drains.** Depending on the severity of the surgery, there will be one or two chest drains placed. These flexible tubes drain air, blood, and excess fluid away from the surgery site and out of the body. Doctors and/or nurses will check these drains and record output several times a day. To avoid occlusion (blood clotting and blocking off the drain) they will stretch and massage the tubing. This does not hurt your child because the tube is four to six inches into the chest cavity, and secured on the outside with stitches. Once the minimum amount of daily output is reached, a doctor will snip the stitches and remove the

drains, which can be scary for your child. Usually the child will take one big breath as the doctor pulls the tubing out. The removal is over very quickly and is not painful.

□□□□□□ **Central line.** The central line is an IV stitched in, usually in the upper torso or neck where veins are larger and give better access. A central line is used to administer medicine, fluids, or nourishment into a vein. Central lines are typically used in more critical cases that are admitted to the Pediatric Intensive Care Unit.

□□□□□□ **Nasal Gastric (NG) Tube.** This is a tube placed through one nostril into the stomach. Breathing is helped indirectly by decompressing the stomach. Children with feeding issues may also use them to receive liquid nutrition.

□□□□□□ **Oral Gastric (OG) Tube.** An oral gastric tube is placed down the throat to the stomach, and performs essentially the same function as the NG tube.

Endotracheal Tube (ET Tube). Typically used only during surgery, the ET tube is passed through the nose or mouth to the opening to the lungs and connected to a ventilator to provide additional air to the lungs mechanically. While intubated the child is not able to speak because the tube passes through the vocal cords. The child also cannot cough up mucus, therefore, a nurse will remove mucus from the ET tube by suctioning. Outside of the surgical room this also is only used in severe cases admitted to the PICU.

Monitors

A computer screen above your child's bed may display the following information:

□□□□□□ **Heart Rate** – measures heart beats per minute, shown in red.

□□□□□□ **Respiration rate** – number of breathes taken per minute, shown in white

□□□□□□ **Oxygen saturation** – measures the amount of oxygen in the blood, shown in blue. Your child will wear a band-aid or clip with a sensor attached to it.

□□□□□□ **Blood pressure cuff** – is set on a timer to automatically check and record your child's blood pressure at a frequency based on the doctor's orders.

Central Venous Pressure – is measured to monitor fluid status and heart function.

Other monitoring may include:

□□□□□□ **Chest x-rays.** Chest x-rays may be taken every morning as necessary to watch for fluid build up, usually in PICU patients.

□□□□□ **Blood Gases** either Arterial (ABG) or Capillary (CBG) or Venous Blood Gases (VBG). Blood drawn from a capillary, vein, or artery which is sent to the laboratory to measure how well air is passing in and out of the lungs.