

Planning for Your Child's Surgery: What Parents Need To Know Before, During and After Their Child is in the Hospital

Introduction

Parents are an important part of the health care team when a child needs surgery. They are often called on to help their child by providing information and comfort, and advocating for their child's needs. Parents often assist with their child's nursing care in the hospital and then take on all care-giving duties when the child is at home recuperating.

Some surgeries are planned and allow the family time to get all of their questions answered ahead of time. Other times an emergency requires immediate surgery. This fact sheet is designed to offer suggestions to help parents prepare for both kinds of surgery. The goal is to make the child's experience with hospitalization, surgery and recovery as smooth as possible. This can benefit not only the child who has OI, but the entire family as well.

Before Surgery: Planning

Become well informed. Taking care of your child after an operation will be easier if you begin preparing before the surgery occurs. Parents are often asked to explain medical procedures to their child. Before parents can answer their child's questions, they need to have a clear understanding about what will happen.

- Understand the purpose of the surgery.
- Understand exactly what happens during the surgery, how long the child will be in the operating room and the recovery room, and how the child will look after the surgery.
- Understand the hospital's procedures for staying with your child before and after the operation. Find out what you need to do to be present in the recovery room and to stay overnight in the child's room. Children with OI may be fearful of being handled by strangers. Having a parent nearby is calming and reassuring, particularly during the child's first experience with surgery.
- Be aware of the resources the hospital has to offer such as a child life specialist, pain specialist, art therapist, social worker, library, and movies/videos or play rooms for the patient or siblings.
- Many hospitals offer access to a service that provides a free family web page where parents can post information about the child's condition and friends or family can leave supportive messages.
- Ask for information about all medications that your child will receive. Talk to your doctor about any possible drug interactions and side effects.
- Keep a notebook of all information you are given regarding the surgery, recuperation, medication, therapy, etc. It is easy to forget these details later. This also provides a good reference for parents and other caregivers as they trade off for breaks.
- Pre-register your child when possible to expedite admission procedures.
- Inform your health insurance carrier and obtain any necessary authorizations.

Use child-friendly and simple language to explain hospital procedures and the operation to your child. Many hospitals now have child life specialists on staff. They are available to help answer the child's questions and often have special dolls and other toys to demonstrate medical procedures in a comfortable manner. Siblings often benefit from appropriate explanations as well. Information can help decrease anxiety. Many parents believe it is best not to lie to their child, but also caution against telling the child more than he/she can handle. Older children, in particular, may benefit from the opportunity to talk about an upcoming surgery with someone who has already had the same experience.

A pre-admission tour of the hospital can help both you and your child feel more at ease. This can be a good time to get questions answered about hospital rules for parents and visitors, and to learn which comfort items to bring from home.

Explaining OI to hospital staff members as well as other patients and their parents is an important part of being your child's advocate. The OI Foundation's poster *Fragile: Handle Me with Care* can be helpful. Some parents laminate extra copies of the poster or a similar warning sign and tape it to their child's hospital gown when they leave the room. If possible, distribute information about OI during the pre-admission tour, so the staff is prepared before your child's admission.

Other items to discuss with your child's doctor and with the hospital staff include the following:

- **Weight and Medication.** Children with OI are often small for their age. Be sure that your child's chart lists an accurate weight and discuss how your child's size may affect the dose of all medications.
- **Blood Transfusion.** If major surgery is planned, discuss with your doctor how to prepare for blood transfusion and ensure the safety of the blood your child receives.
- **Adaptive Equipment.** Ask about the need for adaptive equipment while in the hospital and/or at home. Examples include a wheelchair, adjustable tables, bedpans, crutches, moleskin, cast supplies, and cast shoes. Be sure to order equipment ahead of time to ensure proper size and to have the opportunity to become comfortable using it.
- **Casts.** Inquire about cast options to accommodate your child's age and stage of development. Discuss the shape and type of cast and whether your child will be able to sit, stand or lie down. Because OI bone is fragile, and the weight of a full circular plaster cast can cause proximal limb fractures, light-weight casting materials are preferred. Many orthopedists who are familiar with OI are limiting their use of plaster spica casts. As an alternative a soft spica made of felt has been used to immobilize femoral fractures. If a traditional spica cast is necessary be sure to discuss your child's age and toileting abilities with the doctor.
- **Clothing.** Determine if alterations to clothing will be necessary to accommodate a cast or post-operative swelling.
- **Hospitalization.** Verify the expected length of time in the hospital.
- **Nursing Care.** Inquire if there will be a need for special nursing care and/or parental training.
- **Discharge from the Hospital.** Verify the requirements that must be met before your child can be released from the hospital. Requirements often include ability to walk a specified distance, sit up, use crutches, have a bowel movement, and switch from IV to oral medicines. Children often want to go home as soon as possible.
- **Transport Home.** The hospital can often provide a loaner car seat for infants and toddlers in a cast or a special safety harness to buckle your older child in when he/she is unable to sit correctly with a normal seat belt. The Social Worker or Case Manager can often arrange a medical transport (ambulance) home, if either pain or lack of mobility will prevent your child from being able to transfer to a wheelchair and into a car easily. These professionals can coordinate the insurance paperwork and approval and also make changes if the discharge time shifts.
- **Needs at Home.** Determine if there will be any needs for home health services.
- **Recuperation.** Inquire about the usual length of time spent at home recuperating and when your child can expect to return to school and other normal activities. This is also a good time to check with your child's school about any rules affecting a return to the classroom. Some schools do not permit a child in a spica cast in the classroom. Since it can take time to arrange for a temporary aide or a home tutor, it's a good idea to talk with your child's teacher and school nurse as soon as possible.
- **Therapy.** Determine when to begin follow-up physical therapy or rehabilitation.
- **Follow-Up Care.** Make appointments for follow-up care before leaving the hospital.

Packing. When you pack a bag for your child to take to the hospital, it's a good idea to pack one for yourself. Bring comfortable clothes to wear overnight, slippers, shower items, a toothbrush, hairbrush, and a box of soft tissues.

After Surgery: Coping

Stay informed. If at all possible, arrange to meet your child in the recovery room. This can be very reassuring to your child. When your child returns from the recovery room, find out about the nurses' schedule and the medication schedule, as well as what to do if your child is in pain. Understand what warning signs of post-surgical problems you should watch out for. If your child must be in the ICU, arrange to have a parent or a familiar, trusted adult present at all times. You are your child's advocate. It is up to you to ask questions, report changes in your child's condition, and explain any special OI-related needs.

Stay calm. Your child needs your calm and reassuring presence. Hold hands, sing softly, or, if your child can be out of bed, sit in a rocking chair. Deep breathing together can help your child relax tense muscles. Be positive and reassuring about how your child's incision looks. The swelling will go down, and the discoloration will fade.

Provide comfort measures. It can be a challenge to keep a child who is uncomfortable or in pain calm and entertained. A familiar blanket, pillow or pillowcase, stuffed animal or other small toy can help your child feel more at ease. Choose toys that are easy to play with in bed. Videos are a popular diversion. Bring in old favorites as well as some new, never before seen titles. Books for reading out loud to your child, puzzles and simple games, drawing pictures together, and even blowing bubbles also are entertaining. Many children enjoy listening to music through headphones.

As your child begins to feel better, family visits can be very comforting and entertaining. Knowing that a sibling or grandparent will arrive at a certain time gives your child something to look forward to.

Be alert for behavioral changes. Every child develops his or her own way of dealing with pain or stress. It is normal to be afraid when something hurts. Common reactions to pain include anger, whining, uncooperativeness, regression to babyish behavior previously outgrown, being "too brave" and hiding pain or worry, or becoming sassy and rude. Indicators of pain can be behavioral and/or physiological.

Behavioral indicators of pain include:

- Fussiness
- Restlessness
- Altered sleep pattern
- Grimacing
- Thrashing
- Kicking
- Rigidity or lack of movement (afraid to move)
- Tensing of muscles
- Refusal to eat
- Decreased ability to concentrate or a disinterest in playing or watching TV

Physiological indicators of pain include:

- Increased heart rate
- Change in respiratory rate
- Change in body temperature or blood pressure
- Pupils may become dilated
- Increase in amount of perspiration

Pain Management is a major area of concern. It is very difficult for parents to see their child in pain. You should expect that your child will be in severe pain during the first 24 hours and decreasing pain for at least several days after that. You can explain to your child that the pain will decrease and that medicine is available to help control the pain but doesn't always work quickly enough. Be emotionally prepared to distract your child while waiting for the medication to take effect.

Children show their pain in a number of ways both verbally and non-verbally. Pain intensity scales are used in hospitals to rate pain from "no pain" to "the worst possible pain." When discussing the use of pain medications, be sure to ask about possible side effects including suppression of respiration, disoriented mental state, or constipation. Some parents advise keeping a list of all medications that the child receives while in the hospital. This kind of log will help you keep track of when a dose was given and when the next dose is due.

You can inform the nurse if your child's pain level has changed. You can ask for a cold or heat pack. You also can help with pain management by informing the hospital staff about how your child has reacted to pain in the past and what worked to relieve it.

Medication can be given to children in a number of different ways. Liquids, pills or intravenous medications are the most common methods of pain control. Medication is often given intravenously at first and later changed to medicine given by mouth.

- **Patient Controlled Analgesia (PCA).** The patient has some control over dosing by pushing a button on the pump to deliver a pre-set amount of analgesic, such as morphine, through an IV (intravenous line). Parents are instructed not to press the button for their child.
- **Intermittent IV Analgesia.** A dose of medication is given automatically at set intervals through the IV.
- **Oral Analgesia.** Medication is given as a pill, tablet, or liquid. Some medicines have a bad taste. Find out ahead of time if your child's medicine can be flavored by the pharmacist or disguised in food. Many hospitals keep a supply of applesauce, ice cream, and popsicles in a refrigerator near the nurse's desk for this purpose.
- **Other types of pain medication** include rectal suppositories, injections into the muscle, and skin patches.

Treating Different Types of Pain

- **Mild Pain** may be treated with Non-Steroidal Anti-Inflammatory Drugs (NSAIDS). These include ibuprofen, Motrin®, Nuprin®, and Advil®. Since these drugs can cause gastric irritation, it is recommended to take them with food or milk. All of these drugs interfere with blood clotting and may cause postoperative bleeding. **Do Not** give aspirin to children.
- **Moderate Pain** may be treated with NSAIDS combined with an oral opiate. Examples include Tylenol® with Codeine or Vicodin®.
- **Moderate to Severe Pain** may be treated with an oral opiate.
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Side Effects: All pain medications can have some side effects, but not every child will experience them. The most common side effects of pain control medication include nausea and vomiting, constipation, itching, sleepiness, and slowed breathing. These can be treated, and any questions should be discussed with your child's doctor or nurse.

Other Discomfort

- **Itching.** Do not put ANY foreign objects (pencils, rulers, coat hangers) inside the cast. The risk of injury is too great. Antihistamines can help with severe itching. Tapping on the cast above the spot that itches may provide relief.
- **Muscle spasms** contribute to pain. They can be treated with a relaxant. You can request a prescription prior to discharge, so the medication is available without delay if needed at home. If your child has previously had a problem with spasms, ask the doctor, nurse or pain specialist about options for preventing and treating them.
- **Anxiety** can be a major contributor to the discomfort experienced by your child. If necessary it can be treated with medications such as Versed or Valium.
- **Fever** is very common in the first few days after surgery. It is a response to the surgery and usually subsides. Taking deep breaths helps expand the lungs and minimize fever. You and your child can practice deep breathing before surgery.

Pain Medication Prior to Discharge: Discuss the timing of the discharge and travel plan with your child's nurse and pain specialist. Arrange to time the discharge soon after a dose of pain medication to minimize discomfort on the trip home, which often involves more movement and positions than the child has experienced in the hospital. If you have a long trip, fill any prescriptions ahead of time so you have all medication on hand when needed.

Additional Post-Operative Suggestions

- Give your child plenty of liquids to drink.
- Give your child stool softeners as directed by the physician.
- Encourage deep breathing and coughing. (Children can blow bubbles or use an Incentive Spirometer.)
- Anti-emetic medications can help control nausea and vomiting.
- Antihistamine can reduce itching.
- Encourage your child to rest.

Going Home: Being released from the hospital usually involves meeting with a discharge planner from the hospital, your child's surgeon and often a nurse practitioner. This is the time to review all instructions regarding home care, transportation, medications, physical therapy and follow-up appointments. At the end of this fact sheet a one-page outline is included as a tool to help parents make sure that all of their questions are answered. Even if your child has had many surgeries, do not assume that all of the instructions will be exactly the same. It is

important to have a phone number for someone at the doctor's office who will answer questions as they arise once your child is home.

Before your child is sent home, be sure you are comfortable with all areas of home nursing your child will need. Sometimes this involves learning a new skill or becoming emotionally prepared to deal with unfamiliar tasks that cause your child discomfort. Know how to reach the doctor day or night, what to watch for, and what to do if you have questions or if there is a worrisome change in your child's condition, dressings or cast before the scheduled post-operative checkup.

Home Care

Positioning: The caregiver needs to be extra careful when moving a child who has an incision or is in a cast. Support the child's entire body and be aware of where the noncasted limbs are, so no new injury occurs. Casts add a lot of weight so your child will be much heavier. Use good body mechanics to avoid injury to yourself or your child. Also be aware that children with OI can fracture above or below the cast, just from the weight of the cast.

Pain management usually continues at home. Parents need to be absolutely certain about dose and schedule and what to do if a dose is missed or delayed. Keep a written schedule that lists the name of each medicine, what it is for and how often it can be given as well as the dosage. List the times your child actually takes each medicine. This is useful when you have "shift changes" at home between parents and caregivers and provides a useful record of the pain level over time.

Children in a cast, especially those in a spica cast, often have difficulty sleeping. Depending on age, and size, your child may be more comfortable sleeping propped up in a recliner or bean bag chair than in bed.

Managing dressings placed over a wound requires some special instruction. Parents can practice changing the dressing, with nurse supervision, before their child is discharged from the hospital. It is particularly important to learn how to remove any adhesive without damaging already fragile skin. Before discharge, assemble ample supplies at home

Cast Care Do's

- Encourage your child to move fingers or toes frequently to reduce swelling and prevent joint stiffness.
- Keep the cast as clean as possible by keeping out dirt, lotions and food.
- Elevate the casted limb on a pillow and apply ice to reduce swelling.
- Inspect skin at the cast edges and beneath the cast for any change in temperature, color or texture.
- Inspect the cast for odor or drainage.
- If skeletal pins are in place, clean around the pins as directed by physician or nurse.
- If the lining inside the cast gets wet, it will irritate the skin. Use a blow dryer set on COOL to blow air into the cast until padding is dry. **Never** use a blow dryer on a warm/hot setting. Air that hot can burn fragile skin.
- Apply moleskin around the cast edges to protect the skin.

Cast Care Don'ts

- Never get a cast wet.
- Never cut a hole in the cast or split it open.
- Don't use objects such as a pencil, ruler, toothbrush, or food items to scratch underneath the cast. Such items can get stuck inside the cast and scratching can cause severe skin damage.
- Do not break off rough edges. They can be lightly sanded down with an emery board until smooth and moleskin applied around the edges.
- Don't remove the cast by yourself.

Cast Complication Warning Signs

- Your child complains of excessive pain or an increase in pain.
- The cast feels too tight and the feeling does not improve after elevating the limb.
- There is persistent numbness or tingling in the limb.
- Your child experiences pain in one place under the cast, and changing positions does not bring relief.
- The limb continues to swell after elevating it.
- The limb feels cold or looks discolored.

Preventing Complications of Immobility

- **Cardiovascular:** Perform range of motion exercises with the unaffected limb to promote venous circulation. Such exercises minimize muscle and joint stiffness, and swelling. Exercise also reduces the risk of vein thrombosis.
- **Bowels:** To prevent constipation, increase fluids, which will also aid in keeping the urinary tract healthy. Add fiber to your child's diet, use stool softeners as directed by the physician and ensure your child gets a well-balanced diet to promote healing.
- **Skin:** To prevent areas of skin breakdown, re-position your child frequently. An egg-crate style mattress cover can relieve areas of pressure. Keep your child's bed free from friction sources like wrinkled sheets or particles of food.
- **Infection:** Watch for signs of fever or increased pain. Check the incision for visible signs of redness, edema (swelling), unusual odor, or drainage.

Managing Activities of Daily Life

Toileting: Children in a short leg cast or those who have an arm cast may need a moderate amount of assistance. It may be possible, with younger children, to hold the child over the toilet. A bedside commode can be a good solution for an older child recuperating from leg surgery. It can be put directly up against a bed or coffee table to allow the child to slide into position without bending the legs. In some instances insurance will cover this item and it can be ordered by the doctor's office or hospital ahead of time for delivery along with other aids.

Toileting issues and the Spica Cast:

- Before the cast is applied, be sure the doctor is aware of your child's toileting ability.
- Before the cast is applied, inquire about making the cast's opening for toileting as big as possible.
- A large kitchen funnel may make it easier for your child to use a bedpan.
- Disposable diapers can be folded down at the front and back edges approximately 1 inch and then tucked under the inside edge of the cast around the pubic area.
- Cosmetic pads and different sizes of feminine napkins are also useful.
- Plastic wrap can be tucked in around the edges of the cast for extra protection.

Bathing and hair washing: Some of the new waterless products available through many drug stores offer an alternative for washing hair and bathing. If you have difficulty locating these products, ask the druggist to order them. A sponge bath often will be necessary when your child can't be moved. Covering the cast with plastic wrap or a plastic bag will protect it near water, especially once you can give your child a shower or bath. Placing your child on the kitchen counter, or in a chair with phone books and pillows, and using the sink can make hair washing possible if this is done safely. Some beauty parlors or barbershops may be willing to place your child on pillows to reach the sink level for hair washing.

Eating: A healthy diet will promote healing. Immediately after surgery, many children lose their appetite due to pain and the effects of anesthesia. If the child will be significantly immobilized for a long period of time, consult with your doctor and/or a dietician for advice about nutrition. Weight gain after surgery can reduce mobility and put added stress on already fragile bones.

Dressing: After surgery or a serious fracture, children often have to re-learn previously mastered skills for dressing, undressing, toileting and walking. Provide encouragement and the opportunity to regain these skills. Additional adaptive equipment may be necessary for a short while. Clothing may need to be altered to accommodate the cast. Opening seams and using Velcro-type fasteners, athletic pants that zip up the sides, going to a larger size and using extra-large socks (to protect swollen feet and ankles) may be helpful.

Schedules: Every household has its own rhythm of daily and weekly activities. As soon as possible, return to a normal schedule. Allow visits from your child's friends as early as recuperation allows. It can provide a real lift to everyone's spirits. As your child heals, return to your usual expectations for age-appropriate behavior. Encourage your child to return to school and resume time with playmates and friends as soon as possible. Plan for your own return to work and other activities too.

School: It is important to keep in close contact with your child's school. Be sure to know the procedures for getting schoolwork, arranging for home instruction and, if necessary, hiring a part time aide for the return to school. If your child will be receiving home instruction, talk with the teacher about how to keep the child connected

to classmates. Ideas from students and parents include conference calls, contributing to a class project or sending e-mails to the class. Many schools have web sites or telephone systems where teachers post assignments and other useful information.

Spica Cast Concerns: When a spica cast is necessary, parents will need to take special precautions when lifting and moving their child both to protect their own backs and to protect the child from additional injury. Many parents recommend using bean bag chairs to help comfortably position the child. Because of the nature of a spica cast, keeping it clean, dry and odor free is especially difficult. See information in the section on “toileting.”

Physical Therapy: PT is part of the recovery process for children with all types of OI. Often it begins with activities at home. Maintaining strength in the limbs that are not in a cast and regaining strength after the cast is removed are important goals.

Other Family Issues

Take care of the caregivers. Parents suffer a great deal of fatigue and stress when a child has surgery. It is normal to experience feelings of guilt, anger, sorrow, depression, fatigue, and stress. The hospital routine is very different from normal daily life and can be disorienting. Responsibilities for laundry, meals, housework, other children, and jobs can't be ignored for very long. Parents suggest the following coping strategies:

- Schedule phone contact with friends. They can offer much needed support.
- Use e-mail lists as an efficient way to keep relatives and special friends informed about your child's progress.
- Because children with OI may need multiple surgeries, it can help to plan ahead and develop a network of friends and relatives who can help out at home or during hospital visiting hours.
- Allow friends and family to help by cooking meals, doing laundry, and running errands.
- Parents must allow time to take care of themselves. Recognize when a break is needed and take it.
- Don't forget to get some sleep.

Siblings also feel the stress of having a brother or sister in the hospital or at home recuperating. It is not uncommon for siblings to experience many strong, even conflicting feelings, such as anger, jealousy, anxiety, deep concern for the hospitalized brother or sister, and resentment about being ignored. Having a relative such as a grandparent, aunt, uncle, or other adult friend provide some attention, listen to concerns, and help keep the siblings' routine somewhat on schedule can help them cope in a healthy manner.

Parents are encouraged to keep siblings informed of progress directly. Let them know that they are important players in the entire process. Call them from the hospital regularly, be honest and positive, and provide age-appropriate information about what their brother or sister is experiencing.

Keeping a healthy perspective can help the healing process. Recovery from a surgery can be hard work and can take a long time. It is easy to get bogged down in the work and seriousness of the experience. Many parents who are experienced with the surgeries that are part of managing osteogenesis imperfecta suggest looking for opportunities to share a special moment with your child. Seek ways to have fun together. Keep laughter on the agenda as part of post-operative care.

The OI Foundation and Michelle Hofhine, RN prepared this fact sheet based on Ms. Hofhine's presentation at the 2002 OI Foundation National Conference. Ms. Hofhine is Clinical Pediatric Supervisor for Home Health Agency in California. She is also the mother of two children, one of whom has OI.

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