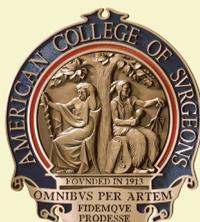


Who Will Hold *My* Hand?

A GUIDE FOR PARENTS WHOSE CHILD NEEDS AN OPERATION



FROM THE AMERICAN COLLEGE OF SURGEONS



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Who Will Hold *My* Hand?

A GUIDE FOR PARENTS

WHOSE CHILD

NEEDS AN OPERATION

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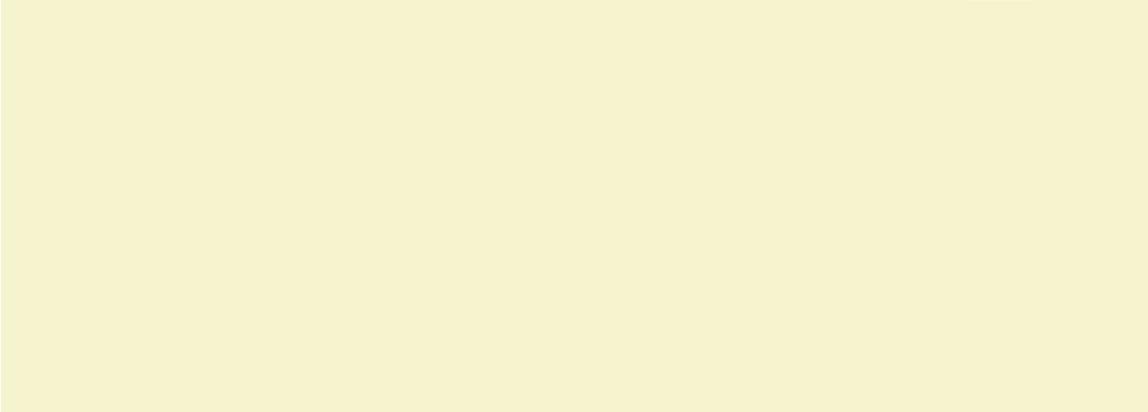
This book is dedicated to the parents who have taught me so much; to the parents whom I hope will be a little less anxious after reading this book; and to Nicky, without whom this book would not have been written.

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Introduction



*“The doctor explained everything,
but once I heard the word **surgery**,
I could not hear anything else.”*

Chances are if you’ve never had this experience, your child has never needed an operation. Or maybe the doctor didn’t explain everything, and you went through the agony of not really knowing what was happening to your child. The idea for this book occurred to me during my year as President of the American College of Surgeons in 2005–2006. It is intended for parents whose child needs an operation and who haven’t the foggiest idea how to handle anything: themselves, the doctor and other medical personnel, their child, and other family members.

Why a “hand-holding” book? Not too long ago I retired from the active practice of surgery after 32 years of being a fully qualified pediatric surgeon at a children’s hospital. Some years ago I had a young patient I will call Cherry—not her real name. Her father brought her to see me because of a small, smooth lump on her chest wall. Since I could not tell what it was, I advised removal. During the operation, which I thought would be very simple with a happy outcome, I realized that the lump was a **tumor** (boldface terms are explained in the glossary at the end of this book) that went deeper than expected. It turned out to be **malignant** (cancer). I told

the father that Cherry would need further treatment and explained how we would take care of her. In the middle of my explanation, he broke in and asked, “Who will take care of *me*?” I realized he had no idea what to do, what to ask, or how to talk to his daughter.

Since that time, I have tried hard to explain not only the conditions my young patients have that require an operation but also how their parents can navigate the complex system that is a medical center.

Parents like Cherry’s father have taught me much over the years. This book compiles their experiences as well as my own. I hope it helps to take away a little of the helplessness and fear that parents feel when they hear the word *surgery*. My goal is for this book to ease some of the pain of learning how to deal with a situation you did not welcome in the first place.

The book is divided into four parts. Part 1 walks you through what happens when your child is in the hospital for a surgical procedure. It also introduces you to the health care workers you likely will encounter: the doctors, nurses, social workers, and other health personnel. This section also includes a short, simple explanation of diagnostic tests that your child may need before or after an operation.

Part 2 focuses on questions: what to ask, whom to ask, when to ask, and how to ask. In Part 3, I discuss some specific surgical procedures—both simple and complex—in the child and a few in the newborn. This section is for parents of children whose surgeon will be a general pediatric surgeon like myself. For that reason, I do not describe all the possible childhood conditions needing an operation. There are many surgical conditions

treated in other medical specialties. A few examples are ear, nose, and throat; urology (urinary system); neurosurgery (brain and spinal cord); and orthopedics (bones and muscles). I have left details of operations in those areas to the experts. My knowledge is not concentrated there.

Neither do I address chronic conditions except when these problems become evident at an acute stage. It is my experience that by the time a child enters a chronic stage of illness—for example, cancer—the parents have become experts on the hospital system and could write this book better than I can.

Part 4 lists other resources that may help you. It also has a glossary of terms that you can easily refer to as you read the book. The glossary should take the mystery out of the jargon that medical people use.

A final word. In this book, I usually refer to “the doctor” as “she.” Since I am female, I will use the feminine gender. I offer my apologies to my male colleagues and hope that they will understand, because I have endured the generic “he” all my professional life!

PART 1

Let's Walk through the Day of the Operation





Chapter 1

What Happens Before and After the Operation?

When you first enter a hospital system, it seems as if there are an overwhelming number of health care professionals. All seem to play some role in your child's care even if you don't know who they are. The familiar face of your pediatrician is not there. That physician has handed over the care of your child to a group of competent care providers whom you probably do not know. Most of them will be polite enough to introduce themselves to you, and some will explain their role. But you can't count on that happening, and you may be so overwhelmed that you can't remember who Miss X. is or where Dr. Y. fits into the care team. Therefore, in Chapter 3 I will tell you in detail the kinds of jobs the people you will meet have and what their roles are in taking care of your child while he or she is in the hospital.

First let us walk through the day of the operation. If you and your child's doctor planned the operation and it was not an emergency, it may be called an **elective procedure**. This term means that you elected, or chose, a time for the operation that was convenient for you and the surgeon. The operation may be elective but it is still medically necessary.

GETTING READY FOR THE OPERATION

For an operation you have scheduled in advance, you will have already been told all about the operation your child needs. Now you and your child arrive at the hospital admitting office at the appointed time. An admitting clerk will log your information into the hospital's computer system: child's name, address, referring doctor, surgeon, insurance (which you may need

If your child sneaked something from the refrigerator, don't hide it from the hospital staff.

to verify, so bring your insurance card with you), and so on. After this rather tedious process, the clerk will ask you to sign a general consent form allowing the hospital to do general diagnostic tests such as blood work, and **X rays** if needed. This form is not consent to do the operation itself.

Next, a wrist band to identify your child will be placed on his arm. Do not remove this band until your child leaves the hospital. Be sure that you have answered the question about whether your child has allergies and if you have any restrictions on what may be done. (Jehovah's Witnesses, for example, do not permit blood or blood products to be given.) If so, let the clerk know and make sure it is written down.

You will then be taken to see your first medical person, either nearby or in another part of the hospital. This person may be your doctor or a trainee such as an **intern** or **resident** physician. (We'll get to definitions of these people in Chapter 3.) Or the person may be a nurse or a **nurse practitioner**, a special nurse who has advanced training. The medical person will take a history from you about your child's condition and will ask lots of other questions about his health.

The medical professional will ask when your child last ate. You should already have received instructions by phone or letter that your child can have "nothing by mouth" (**NPO**). Before an operation a patient must not eat or drink anything for a certain time, long enough for the stomach to be empty. For adults this time is standard; for children it varies depending on their age and medical condition. Follow these instructions exactly. They are important to make sure your child can safely be given **general anesthesia**. If your child sneaked something from the refrigerator, don't hide it from the hospital staff. You must reschedule the operation.

Finally, the medical person will perform a brief physical examination of your child. He should not have a cold or symptoms of the flu. If that is the case, you need to call and inform your surgeon before the day of the operation. You may need to reschedule the operation. You also need to call your surgeon if your child was exposed to a contagious illness, such as chickenpox, measles, or mumps, or got head lice within the few weeks before the operation.

The admitting process is now done, and you and your child will go to a preoperative area to wait.

(The registration process might take place a day to a week before the actual operation. If you went through “preadmission,” you would go home and return on the day of the operation.) In the preoperative area, your child will be assigned a bed. He will probably be undressed by this time and have on one of those dreadful gowns that ties in the back, not at all encouraging modesty.

Now a doctor appears, perhaps your first doctor of the day. It will be the anesthesiologist or an **anesthesia** resident who will explain what will happen when your child goes to sleep.

You might encounter some medical jargon that you don't understand. Stop! You must be sure you understand all of this part. If a doctor uses terms you don't know, ask her (or him) to explain. Keep asking questions until you understand exactly what will happen.

You may be invited to be present at **induction**, that is, the start of anesthesia, and stay until your child is asleep. This process could take place in a special room or in the **operating room** (OR). If it is in the OR, you will receive a gown that looks like a “bunny suit” to cover your street clothes. As soon as your child has fallen asleep, you must leave, because the doctors and nurses have a lot to do. They will put monitors on your child and get him ready for the operation.

Not all hospitals allow parents to be present at anesthesia induction. If that is the case, your child will receive a **sedative**, usually by mouth, or sometimes in the **rectum**, or, rarely, by an **intramuscular** shot (**injection**) into the arm or leg. This medicine may make the child act drunk, and the child will often laugh. That can be very reassuring to parents, who could use a sedative themselves by this time!

Children often are irritable or cry as they awake from anesthesia.

Before the operation starts, you may see the surgeon. Or you may not if she was doing a procedure on another child before yours has his operation. If you have questions before your child goes to the operating room, you can insist on seeing the surgeon first.

A word about patient safety. Operating on the wrong side or in the wrong place in the body is less common than the press would have us believe, but errors can, and do, occur. Most hospitals now have a rule that the site and side of the operation be marked. There are different ways of doing this, and the doctor or hospital staff should tell you the surgeon's or hospital's rules. Pay attention to this step. You don't want to learn that the surgeon, instead of fixing, say, a left-sided hernia, has made an **incision** on the other (wrong) side. For the same reason, many hospitals have instituted a time-out policy in the operating room, so the whole surgical team agrees that the correct operation is being performed in the correct site on the correct patient. Ask your surgeon about this if you have any concerns.

DURING THE PROCEDURE

After your child has been taken to the OR, or once he is asleep if you are present for anesthesia, you will go to a waiting room, where you will try not to gnaw your fingernails down to the quick. If the operation will last a long time, you may receive reassuring messages from the surgeon or the OR nurses from time to time. The person who gives you the messages may not be a medical person and likely will not have any information other than the message. So try not to ask questions at this time because the messenger may not know the answers.

Also try not to time the surgical procedure. Parents always want to know how long they will be separated from their child. While the surgeon may tell you approximately how long the operation will take, remember that this is only a general timeframe. It could take more or less time. (Less

time would be unusual, as surgeons rarely overestimate procedure length.) The preparation before the operation takes time. The anesthesiologist will not permit an operation to start before all the monitors are on and working (heart rate, blood pressure, breathing, and so on). It may take a while to start an IV (an **intravenous** line), particularly if the child is small. Don't worry; he will be asleep when this part happens. After the operation is finished, the surgeon usually will wait until your child is waking up before leaving to tell you how the operation went. This stage, too, takes time. I realize that a minute is a long time when you are anxious. So leave your watch at home or turn it backward on your wrist during the operation.

After what seems like an endless length of time, the surgeon appears. I hope that your surgeon has a big smile on her face. I have always come out of the operating room smiling. I want to reassure parents that their beloved child is fine and is waking up.

As your surgeon tells you the details of the operation, make sure you understand everything she is saying. There is no such thing as a stupid question!

RECOVERY

Where your child goes to recover from anesthesia may depend on whether the procedure is inpatient (meaning that your child will stay in the hospital one or more nights) or outpatient. An outpatient operation does not require an overnight stay. Your child can go home on the same day the operation is performed. Some facilities call this same-day surgery or day surgery.

Day surgery

Many operations no longer require a hospital stay. If your child is having an outpatient operation, you will wait a little longer in the waiting room after the surgeon has finished giving you details of the operation and postoperative instructions. The recovery nurses will also give you general postoperative instructions. These may be oral or written.

*In the ICU, you likely will meet a whole new set of doctors called **intensivists**.*

Hospitals differ on what happens right after the operation is over. You may be allowed into the **recovery room**, so your child sees you as he wakes up. Or your child may be transferred to another room once he is fully awake, and you join him there. Some hospitals have rules on how many people can be in recovery with the patient.

Be aware that children often are irritable or cry as they awake from anesthesia. Their crying may or may not be related to pain. It may stem from confusion about where they are and what has happened. They may need pain medication or antinausea medicine or both, and they will receive these drugs as needed in the recovery room.

The length of time your child spends in recovery depends on the procedure, the amount of anesthetic he received, and whether there are any potential problems that need monitoring.

When everyone is satisfied that discharge is safe, you will be allowed to take your child home.

Inpatient operation

If your child is to be admitted to the hospital after the procedure, you may be directed to the hospital room and not go to the recovery area at all. As I said previously, hospitals have different policies. A typical hospital room and what happens while your child is there are described in Chapter 2.

INTENSIVE CARE

If your child has a complex and/or a long operation, or is very ill, he or she may need to stay in the **Intensive Care Unit**, or Critical Care Unit, as it is often called. Here a single nurse is assigned to only one or two patients. When this level of nursing is no longer needed, the patient is discharged to a regular hospital room.

When the operation is very long or involves complicated procedures, your surgeon and anesthesiologist may decide it is safer to have a machine called a **respirator** breathe for the patient. This machine allows for much heavier sedation. In addition, the patient may need strong medications, for example, to support blood pressure, which need to be monitored hourly. This would be an impossible task for nurses with several patients to care for, as is the case in a regular hospital room. For these reasons, you may find your child in the Intensive Care Unit, where he will almost always have his own nurse to take care of him.

The Intensive Care Unit can be a scary place if you have never been in one and if it is your child there. Multiple wires run to beeping machines, tubes are all over the place, and in the middle of what may look to most people like a confused mass of things—pale and maybe unconscious—is your child. If you know your child will need intensive care, try to arrange for a tour of the place before the operation. Go without your child. Chances are he won't remember this part of the hospitalization.

In the ICU, you likely will meet a whole new set of doctors called **intensivists**, who specialize in intensive care. Since they often work in shifts, there may be more than one of them.

Your surgeon and her team also will visit patients. But your child's nurse is your best bet for getting all the procedures explained because she or he is almost constantly by the bedside. An intensive care nurse has sophisticated knowledge, knows a great deal about your child's condition, and usually can explain everything as clearly as, if not better than, the doctor.

If your child is at a teaching hospital, you will usually be asked to leave during rounds, when the intensive care team gathers round a patient bed to discuss the case. It is important to be understanding of this policy. Other patients are discussed, and for the sake of their privacy, it is best for you not to be there. Plus, wouldn't it be awful to overhear grave talk about another patient, think they are talking about your child, and have unnecessary anxiety?

You may or may not be able to sleep in this unit. If not, there may be parent sleeping accommodations close by, usually in the hospital, depending on space availability.

The size of the scar will depend on the size of the incision.

A word here about restraints. Small children or heavily sedated older children cannot understand that pulling out their IV or a tube in their nose or their chests is harmful. They will, therefore, try their best to do this. So they need to be gently restrained, usually with cloth tapes tying their limbs to the bed. Use of these restraints is tightly controlled by the hospital. Restraints are used only when absolutely necessary and are removed as soon as it is safe to do so.

Hopefully, this anxious time in the Intensive Care Unit will pass quickly, and your child will be able to move to a regular medical-surgical hospital floor, and go home soon.

SCARS

Surgery involves cutting. All healing in the body occurs by scar formation, whether the cut is only in the skin or deeper. So when you ask, “Will there be a scar?” the answer is, “Yes.” The size of the scar will depend on the size of the **incision** (surgical cut) needed. For example, a small lump in the neck measuring half an inch would not need much more than a half-inch cut and therefore would result in a half-inch scar.

These days many operations are done using **minimally invasive surgery**, sometimes called “keyhole” surgery because the incision is as small as a keyhole (See Chapter 2). In these cases there are several small scars, which are much less obvious than a single large incision.

Scars also can be internal, in muscle and even deeper. Scarring inside the belly, for example, may cause loops of bowel (**intestine**) to stick together. Occasionally this scarring will cause blockage of the intestine. This internal scarring is referred to as **adhesions**. It is always more difficult to operate in the same area of the body a second or third time because of these adhesions.

When a cut is made, it must be sewn closed. Usually the surgeon uses stitches (called sutures) that the body eventually absorbs. These stitches disappear. The surgeon may use an invisible stitch that weaves back and forth from one side of the incision to the other. This stitch is called a “subcuticular” suture. It usually dissolves and is much easier on children because it does not have to be removed.

Sometimes the skin may be sewn closed with stitches you can see and that need to be removed. Less often, staples may be used. These also need to be removed with a special instrument.

Parents often ask me, “Do we need a plastic surgeon to do a cosmetic closure?” Most surgeons are trained to do a cosmetic closure (minimize the visibility of the scar) and pride themselves on doing as neat a job as possible. But for extensive operations on the face or other noticeable area, your surgeon may well ask a plastic surgery colleague to close the final incision. Usually ordinary insurance does not cover a special type of surgical closure. Check with your insurance company if you want a plastic surgeon involved.

A word of caution here. Healing and scar formation may vary in different parts of the body. The face and neck heal very well and very quickly, and scarring is usually minimal. In thicker areas, particularly over large muscles where movement is inevitable, such as the larger muscles of the arms and legs, healing is slower. The scar may spread and not end up as a thin line. In addition, people heal differently. Darker-skinned people may produce scar overgrowth or “keloid” formation, which means that the scar becomes very thick and unsightly. This kind of scarring sometimes may occur even in light-skinned people, especially in skin that has had trauma, such as a burn or infection.

Let me mention one possible complication. Occasionally a surgical wound (the incision) may become infected, especially if the surgical condition was caused by infection—for example, in appendicitis, an infection of the **appendix** (discussed in Chapter 8). The wound becomes red, warm, and painful. The infection may be on the surface of the skin and can be treated easily with cloths soaked in warm water.

Sometimes the infection may go deeper. Pus can accumulate, and the wound may need to be reopened to drain the pus. When a deep infection occurs, the wound is left open to heal itself. In these cases, the scar is inevitably wider than if healing took place without an infection.



Chapter 2

What Kind of Operation Will My Child Have?

In Chapter 1, I briefly mentioned inpatient (day surgery) and outpatient surgery. In this chapter, I will explain what they involve. I'll also talk about what happens if your child needs an emergency operation.

DAY SURGERY

Day surgery, also called same-day or outpatient surgery, is when your child can go home the same day the operation is performed. Most simple surgical procedures performed on children are outpatient operations.

This type of operation can take place at the hospital or an outpatient surgical center. If the procedure is minor, such as removal of a small skin lesion, the doctor can perform it in her office. In this case, the doctor often uses **local anesthesia**. In the hospital, a child almost always gets general anesthesia. This is because children cannot keep still and hate injections, which would be used for local anesthesia.

The surgeon will tell you ahead of time if your child's operation can be done on an outpatient basis. Sometimes, though, this changes, and your child will need to stay overnight in the hospital for close monitoring.

Most simple surgical procedures performed on children are outpatient operations.

INPATIENT SURGERY

The operation is over. It went well, and you are incredibly relieved. After the recovery room stay, let's assume your child needs to stay in the hospital. If the procedure was not complicated, you will go to a regular hospital room until your child is well enough to go home. No one believes that the hospital is a good place to be for a child, so postoperative stays tend to be short—a few days only.

The room might be private, for just your child. Some hospital rooms are for two and occasionally more patients. You should be allowed to stay in the room with your son or daughter. A guest bed or chair bed may be provided so you can sleep. Hospitals vary a great deal in their family accommodations, so be sure to ask about these ahead of time when you plan the operation.

If you have to wait before your child is brought to his room, you might want to go to the hospital's cafeteria now and get something to eat. You'll need your own strength to help your child get well. This is not the time to diet!

You may arrive on the floor (sometimes called a ward) while your child is still in the recovery room. You will wait in the room until the child arrives. I hope the nurse who will take care of your child will have time to introduce herself or himself to you.

When your child comes into the room, he will probably not look like himself. He may have various tubes coming out of his body. We'll discuss these tubes in the next paragraph. If your doctor has not explained the tubes to you, ask a nurse to explain when there is time. First, though, the nurse must settle your child in bed, make sure all the tubes are working, and check that the child is comfortable and has enough pain medication. This may take a while. Tell your child that you will be nearby, even if he is not fully awake.

Tubes

Let's talk about the tubes that a child most often will have after an operation. The tubes may look a bit scary, but they are important for helping get your child well. The most common tube is the **intravenous** (IV) line. This tube pumps fluid into a vein in the hand or arm (or the foot in young children). It provides water and essential salts when the patient cannot drink. The IV also gives antibiotics when needed, as well as pain medication. I'll write more on pain medicine in the next section.

If the operation was done in the **abdomen** (belly), the surgeon may drain the stomach with a **nasogastric tube**. The surgeon inserts this tube through the nose into the stomach. After an abdominal operation, particularly if the intestine was operated on, the intestine may not work for a few days. Fluid backs up into the stomach, and if it is not drained, the patient vomits. The tube feels horrid when inserted, but vomiting would be worse. Particularly with an incision in the belly, vomiting would aggravate pain and could tear loose the stitches.

Fluid coming out of the nasogastric tube is at first often green or yellow **bile**. Bile is made in the liver and aids digestion. It gets into the first part of the intestine through a narrow tube called the common duct. Bile is collected in a bedside container or sucked up into a container that hangs on the wall. Occasionally the fluid is brown. This usually occurs when the tube irritates the stomach. The brown sometimes looks like coffee grounds. It is old blood and not usually anything to be concerned about. When the intestine starts to work again, the volume of the fluid goes way down and the green-yellow color disappears. Once this happens, the tube can be removed.

Occasionally the surgeon places a **gastrostomy** (stomach) tube directly into the stomach during the operation. The tube exits through the skin in the upper left part of the abdomen below the ribs. A stomach tube is used when the child needs drainage of his stomach for a long time or cannot feed by mouth and needs formula put directly into his stomach. It takes about three weeks for a stomach tube to seal in place, so it is important that you or your child do not pull it out during this time. If your child needs this

Kids bounce back more quickly after an operation than adults do.

special stomach tube, the nurses will teach you how to clean it and take care of the tube. Although you may think at first that you'll never be able to take care of the tube, you will become an expert. I can't teach you here, but the nurses will.

If your child had a chest operation, the surgeon had to let air into the chest in order to work. This will be true whether there has been an open (big) incision or several small incisions as with minimally invasive surgery. This air causes the lung to collapse. Remember that the anesthesiologist controls the patient's breathing, so this is not harmful during the operation. Afterward this air must be sucked out of the chest, or the patient cannot use the lung to breathe. The surgeon must place one or sometimes two tubes inside the chest and through the skin. The surgeon places the chest tube low toward the back of the rib cage and between two ribs. A chest tube hooks up to a suction device. It sucks the air and any blood or fluid out of the chest and allows the lung to expand again so it can breathe properly.

Chest tubes usually are removed in a few days. The child will usually need a sedative for the removal of the tube.

Pain medication

Years ago, doctors used to think that children didn't suffer pain like adults do. Now we know better! It is true that children don't worry about pain as much as adults do. Kids bounce back more quickly after an operation than adults do. But kids do have pain, and they will receive pain medicine. They will receive morphine for severe pain. In the past, morphine was given by a painful shot in a muscle. Kids would often say they didn't have pain so they could avoid the injection. Today patients in the hospital receive morphine painlessly, through the IV.

There is a fairly new technique of pain control that is marvelous. It is called patient-controlled analgesia or **PCA**. We can also have parents control the **analgesia** when the child is too young to do it alone. A PCA is a device attached to the IV pump, which contains the pain medicine, usually morphine. The patient or parent pushes a button, and the child receives a carefully calculated dose of medication through the IV. A PCA allows for a constant blood level of medication. It is far more effective at controlling pain than when the medicine is given every few hours. An overdose is not possible. There is a “lockout” mechanism in the device that allows medicine delivery only every 15 minutes and only in the amount that the doctor specified.

A hospital often has a team of doctors and nurses who are specially trained in pain management. They are in charge of keeping your child comfortable with pain medicine. After a few days, depending on the extent of the operation, this team can decrease the dosage of the pain medicine. Or they can change to less strong medicine, such as acetaminophen (Tylenol) with codeine. It can be given as a pill or liquid.

Discharge planning

Discharge planning should start right after the operation. You will need to know approximately how long your child will stay in the hospital. You may need to order home medical equipment.

The nurses should begin teaching home care soon after the operation. Examples include:

- Names and doses of medications your child will take at home
- What you can feed your child
- How to take care of the surgical incision
- When the child can start riding his bike
- How to take care of a gastrostomy

*Today we even have
surgeon-controlled robots.*

If you have social issues, such as problems with transportation or getting time off from work to be with your child, a **social worker** will be assigned to you. If there are complex medical issues, your child may have a caseworker who will help coordinate inpatient care, transition to home, and outpatient care. For children who need **chemotherapy**, an **oncologist** (cancer doctor) and **oncology** nurses will meet with the parents and go into detail about treatment follow-up.

Your surgeon will visit your child at least once a day during the hospital stay. Before discharge, the surgeon or someone your surgeon designates will examine your child to make sure he is ready to go home.

MINIMALLY INVASIVE SURGERY

Adults have enjoyed the advantages of **minimally invasive surgery** for years. Many adults have had their **gallbladder** removed by several tiny incisions, through which the surgeon passes instruments on long handles. Through a little larger cut at the belly button, the surgeon can pass a camera. The camera then projects the inside of the abdomen onto a TV screen in the operating room. This technique is called **laparoscopy**. When minimally invasive operations are done in the chest, it is called **thoracoscopy**. In a joint, it is arthroscopy.

Many operations that used to need a big incision can now be performed through a few tiny incisions, even in newborns and children. As techniques have improved and smaller instruments have been invented, surgeons can do more operations this way. Some of the many small-incision operations that pediatric surgeons perform include:

- Removal of the **appendix** or gallbladder
- Some intestinal operations
- A common procedure for acid reflux disease

Today we even have surgeon-controlled robots whose tiny “hands” can fit through small incisions into spaces that human hands cannot. The surgeon works the robot’s controls at the operating table or even remotely, from a different town. These robots are very expensive, so they are in just a small number of medical centers at this time.

Benefits of minimally invasive surgery include reduced pain, shorter healing time, and fewer complications, such as infection. This type of operation may reduce the need for an overnight stay in the hospital.

Some operations still require a bigger incision, such as removal of cancerous tumors. However, this may not be true in the future as surgical instruments and techniques improve.

EMERGENCIES

If your child has a surgical emergency, you probably won’t have time to run out and buy this book. So I’ll be brief about emergency operations. However, this information should be useful if you ever need to take your child to an emergency department. I’ll use appendicitis (infection of the **appendix**) as an example of a condition that often needs an emergency operation. It is the most common reason for an unplanned operation in children. Appendicitis also is discussed in Chapter 8. You will learn about other emergencies as you read this book.

A case of appendicitis

Dinner is an uneasy time this evening. Your daughter picks at her food and says vague things, like “I’m not hungry” or “My tummy feels weird.” Eventually you let her leave the table. No delays in going to bed tonight. You are fast asleep, when a little voice at your elbow says, “Mommy (Daddy), my tummy hurts.” You get up and feel her stomach, producing a loud “Ouch!” wherever you touch but particularly low on the right side. You just decide to call your pediatrician when up comes dinner. Maybe if you’re lucky, you’ll both reach the bathroom in time. The child’s tummy is really hurting by this time. The pediatrician’s answering service says, “Please go to the emergency room of your local hospital.” So you get yourself and your daughter dressed, and off you go.

You arrive at the **emergency room** just as your child vomits again. A **triage** nurse or doctor checks you in right away and directs you to wait in a waiting room full of people. If it's not busy in the **ER**, which is rare, or if the ER personnel fear that your child is really ill, you will go directly into an examining room. A nurse checks your daughter's blood pressure, heart rate, and breathing rate and takes a short medical history. This involves questions about why you have brought your child to the emergency room. You recount events since your daughter first told you she wasn't feeling well.

An emergency doctor then comes in. With luck, a general hospital will have a pediatrician on duty. In a children's hospital all the ER doctors are pediatricians. An ER doctor is not a surgeon. If the ER doctor thinks your child needs an operation, she will call a surgeon. If you came to a teaching hospital, where doctors train, you will see a surgical resident first. This surgeon-in-training will call an **attending** surgeon to confirm the results of her examination of your child, and the surgeon will come in.

Someone will take blood from your child's arm for a test called a **complete blood cell count** (CBC). The **white blood cell count** usually is too high in appendicitis. The doctor may order an **X ray** or even an **ultrasound** or **CT scan** if the diagnosis is not clear. An IV line is put in your daughter's arm, so she can receive fluids. (Remember the vomiting?) This will replenish fluids she lost and can be a route for antibiotics if the doctor thinks your child needs them.

This process may take several hours. You see an admitting clerk, who asks you the questions mentioned earlier.

If the diagnosis is still not certain, your daughter may be admitted to the hospital. In this case, the doctors observe your child until symptoms go away or until it becomes clear that they must take out her appendix. Don't worry about this extra time. Rehydration is important. Antibiotics need time to work if they are given, and the doctor does not want to operate unnecessarily. It may be the next day before the surgeon decides whether to operate.

Once the diagnosis of appendicitis is clear, hospital workers get an operating room ready. The doctor (maybe a resident) explains the operation to you and asks you to sign a consent form agreeing to an operation for your daughter. You sign only after you are satisfied that you understand the condition and what the surgeon proposes to do. In this case, the surgeon

wants to remove your child's appendix. An operation is needed to prevent the appendix from bursting. A ruptured appendix can cause a severe infection in the abdominal space. This will make the operation and your child's recovery time more difficult.

You may go to the operating area with your child, but you will not be allowed to stay there until your child is asleep. In an emergency, the doctor always presumes that the stomach is full. So the anesthesia must be swift to be safe, and you would be in the way of the doctors in the OR.

You rarely will have a choice of surgeon in an emergency. You'll need to be satisfied with the surgeon who is "on call" for emergencies this evening.

The rest of the procedure is just like an elective—planned—surgical procedure, except that you're probably much more nervous. Chances are your child will spend some time in the hospital after an emergency operation.



Chapter 3

Who Are All these People?

Feeling a little less helpless? Good. Then let's introduce the people who will take care of your child. There are dozens of them, all dedicated to making sure your child gets the best care and is returned to you healthy and happy.

DOCTORS

Doctors who graduate from a U.S. medical school usually have an MD (Doctor of Medicine) after their name. Doctors with an MD are sometimes called allopaths. They focus on treating disease symptoms using drugs and other conventional medical treatments.

Doctors who graduate from an osteopathic medical school have DO (Doctor of Osteopathy) after their name. Osteopathic medicine focuses on the whole patient, with a normally functioning musculoskeletal system playing an important role in wellness, disease prevention, and recovery. Doctors trained in osteopathy are called osteopaths.

For doctors trained in another country—for example, the United Kingdom—the degree may be MB (Bachelor of Medicine) with BS or BChir (Bachelor of Surgery).

Let's start at the top of the chain of command and level of knowledge for doctors. The **attending** surgeon is sometimes called a consultant surgeon. This individual has advanced training in a specialty, for example, an attending surgeon or an attending pediatrician.

Most medical specialties have examinations called "**boards**," which doctors take at the end of their training period, which is usually at least two to three years long. Thus, a pediatrician takes board exams in pediatrics; an intensivist, in intensive/critical care; and a surgeon, in surgery.

*Ask your surgeon if she
is board certified.*

A general surgeon has had at least five years of training as a resident, has passed the boards (called board certified or board qualified), and is therefore qualified to practice surgery. If the doctor completed a surgical residency but has not yet taken the boards, she is considered board eligible. Most hospitals require board qualification/certification for a doctor to be on their staff.

Pediatric general surgeons take boards in general surgery first. Then after two years in a training program devoted to children's surgery, they take boards in pediatric surgery. Some other medical specialties have subspecialty boards for children, but many do not. Ask your surgeon if she is board certified in general surgery and pediatric surgery. It is a good indication that she is well trained.

A teaching hospital will also have doctors who are in training. These doctors have graduated from medical school and are training in a medical specialty before taking their boards. The first year of training is called postgraduate year one (PGY-1), and we commonly call these trainees "interns." Interns are MDs. In the second and later years of post-MD training (which can include five years or more depending on the type of surgeon a doctor wants to become), the trainees are called residents. The final year of training is known as the chief resident year. Pediatric surgery requires another two years of special training after the chief resident year. We call these doctors pediatric surgical chief residents or fellows. These are very advanced trainees, and they have a high degree of responsibility for patient care.

If you are in a children's hospital, it may have a special training program for pediatric surgery. (There are roughly 30 such programs in the United States.) The hospital may have more than one pediatric surgery chief resident. It may call this position pediatric surgery fellow. Pediatric surgery is a sought-after profession and attracts highly skilled and qualified people. In my opinion, you may trust these advanced trainees as you trust your attending surgeon.

At a teaching hospital, you may also meet medical students. They don't have a medical degree yet. These students are in their third and fourth years of medical school. They spent their first and second years in the classroom and the laboratory and now are doing clinical "rotations." Doing rotations means they are getting exposure to various clinical specialties. Medical students are a bright bunch, but don't tax their knowledge by asking them questions about your child's condition. Generally speaking, they will not know the answers to your questions. For a quick reference on the education and training of doctors, see Table 3.1.

NURSES

Now let's get to the nurses. There are all sorts of titles for nurses, and even within the nursing profession there isn't agreement as to titles or even function. And of course there are variations from state to state. Community hospitals tend to have a simple nursing hierarchy: bedside nurses (sometimes called staff nurses) and **charge nurses**. But in a large medical center or children's hospital, there are many more levels of nursing function. I will explain the ones you are most likely to speak with while your child is in the hospital.

Let's talk first about the **licensed vocational nurse** (LVN). In some states this professional is called a **licensed practical nurse** (LPN). Some hospitals call them patient care (or service) assistants or nursing assistants. The important word here is *licensed*. These individuals' scope of practice and skill levels are controlled by the state in which they work. These LVNs and LPNs do much of the day-to-day care on the hospital floor or ward. They take patients' vital signs—pulse, respiration, and temperature—and

blood pressure, and they bathe and feed patients who need such help. They are not allowed to give medications, and they have limited medical knowledge. These nurse assistants report to your child's assigned **registered nurse** (RN) and do not make the care plans for the patients.

You should address questions about your child to the registered nurse, who knows your child's medical condition and has developed a care plan. A care plan outlines the steps in the care as the patient recovers from surgery. It includes all care, such as recording of vital signs, feeding, IV medications, and care of tubes.

RNs may have a diploma from a two-year nursing school, but these days the trend is to have mostly bachelor's-prepared nurses. They have graduated from a three-year nursing school and hold a bachelor's degree. Often referred to as floor nurses, RNs may have eight to 10 patients in their care and also supervise two to three LVNs or LPNs.

Registered nurses are caring people. Consider them your friends. They know a lot, and they are readily available to answer your questions and for parent and patient education. When your child goes home from the hospital, the RN will explain things like what your child can eat, how long you should continue to give your child medications, and when your child can go back to school and resume full physical activity.

On each nursing shift there is a charge nurse who is put in charge based on experience rather than level of education. These nurses are in charge of the whole floor, assign patients to RNs, and usually have no individual patient assignments themselves. You will often see them, however, pitching in at busy times. You should go to the charge nurse if your child's assigned nurse is not answering your questions. This individual also interacts with your doctor, so don't hesitate to speak to the charge nurse as you need to.

Another type of nurse you may encounter is the nurse **case manager**. This nurse usually has a master's degree in nursing. Case managers coordinate patient care across the entire course of the medical condition. They act as a bridge between the inpatient and outpatient services, and they help plan for your child's discharge. These nurses have direct access and input to your child's doctor. They tend to work within a specialty. For example, a surgical case manager will take care of patients who have had an operation or need one. They also may specialize within different areas of

surgery. The case manager also does a lot of parent and patient education. You'll be lucky to have one of these nurses for your child. They will smooth the way for you, especially if your child will need continuing care after the operation is over.

A similar position is the **clinical care coordinator**. This nurse works strictly in the inpatient setting. The care coordinator monitors patient care to ensure quality, helps decide how long the child needs to be in the hospital, and participates in discharge planning. This person acts as a liaison to your insurance company. For example, your insurance company may decide that your child is spending too much time in the hospital. (They do this often!) The care coordinator assesses the situation and works with the insurance company to agree on a time in the hospital that is appropriate and medically necessary. This person will work to get your child home in the shortest time possible that is safe.

There is a big overlap between what the clinical care coordinator and the case manager do in the hospital setting and also an overlap between how care coordinators and social workers (see later) function. So don't be surprised if things are not exactly as I have outlined them here. Other titles you may hear include nurse manager and education nurse manager. These are simply administrative titles.

You may encounter some RNs who have advanced education and training, called **advanced practice nurses**. There are two types of advanced practice nurses: clinical nurse specialists and nurse practitioners. Nurse specialists focus on a particular area of nursing. They may specialize in the care of children with cancer, for instance. These nurses supplement the floor nurses in caring for the special needs of the child and do much of the parent education. They smooth the way for parents who need to learn about procedures their child will have. These people are a great asset to the hospital.

Now let's discuss the nurse practitioners. These are nurses who have a master's degree and who have had extra years of training in a special area. In pediatrics this role is called a **pediatric nurse practitioner** (PNP). In some states nurse practitioners can do some independent practice, which is usually primary or office-based care. In other states, they can work only under the supervision of a physician. In the hospital they usually work under the supervision of a doctor. These nurses are highly specialized

Often the social worker becomes the first line of defense for families.

and have an enormous amount of knowledge. If you have the choice of asking a question about your child of a junior resident or a pediatric nurse practitioner, ask the PNP! They are true physician extenders, and they will also bridge the gap between physicians and floor nurses. They may be predominantly inpatient or outpatient but often work in both areas. They are worth their weight in gold to you and to the physicians they work with. Lucky you if you get to know one of these wonderful people.

I've already spoken in the first two chapters about operating room and recovery room nurses. They take care of your child during and right after an operation. They are similar to the floor nurses with regard to their level of training but are much more specialized in their knowledge and skills.

For a quick reference on the education and training of nurses, see Table 3.2.

SOCIAL WORKERS

I mentioned social workers earlier. Whenever I think of **social workers**, I get a warm, fuzzy feeling inside. These people are some of your best friends and staunchest allies as you try to find your way through the complex health care system. The social worker is an individual trained to view the patient in the context of the whole family. He or she will explore the support systems you already have in place to get through this experience: your family, religious beliefs, education, and finances. Social workers help family members build on strengths they already have but may not know they have. They act as a switchboard to coordinate all the resources needed. They are trained to treat each patient and the patient's family together as an individual unit.

Social work training requires a bachelor's degree, often in psychology or sociology, followed by a two-year program to get a master's degree in social work (MSW). Part of this training includes the theory of psychotherapy. (Social workers, after further examinations and licensing, can practice psychotherapy.) Social workers are well trained in anatomy and human development but do not have advanced training in specific disease states. They also receive training in different cultural systems, so they are sensitive to different ethnic beliefs and values.

At the hospital where I practiced surgery, we automatically called a social worker for each patient to complete a family assessment within 72 hours of admission. Often the social worker becomes the first line of defense for families thrust into a situation where perhaps for the first time in their lives they are not in control. During the hospitalization, the social worker helps you plan any changes you may need to make in your home to help your child progress to being well after discharge. Social workers have resources to deal with school, other siblings, and other family members, and will arrange for home care as needed.

Social workers usually work in teams. They may be assigned to patients with a common diagnosis or on a particular hospital floor. In community hospitals where children represent the minority of patients, there may be only one or two social workers for the entire pediatric team. There is no specified cutoff time in contact with your social worker. You will be allowed to call your social worker after you get home if you need help with problems. Social workers are also a resource for your child's medical personnel, to help with the nonmedical needs of each patient.

THERAPISTS

Other people you might encounter are therapists. **Respiratory therapists** take care of airway (breathing) needs. They attend to ventilators or breathing machines and give inhalation treatments, such as oxygen therapy. They function throughout the hospital, but their greatest value is in the **intensive care unit**, where patients often need a breathing machine.

Physical therapists are trained in the rehabilitation of patients after injury or after some operations (for example, brain or spine surgical procedures). These specialists mostly deal with chronic conditions that are beyond the scope of this book.

Occupational therapists are trained to help patients relearn life skills, for example, feeding or speaking. In some hospitals this work may be done by speech therapists. Again, they mostly work with chronically ill children.

OTHER HEALTH CARE PERSONNEL

There are various other personnel you may meet in a hospital. **Physician assistants** (PAs) have advanced training as physician extenders. They do many of the same tasks that doctors do, such as examine patients, order tests, and create treatment plans. They may even help in surgery. PAs are licensed to practice under the general supervision of a physician. They may not need to be directly supervised by having the doctor present when they provide care.

In general, PAs are not nurses. Their knowledge and skill levels, which are considerable, are a little different from those of nurses. Their training is shorter, and in general they are less knowledgeable about diseases. Still, the role of PAs overlaps quite a bit with advanced practice nurses in some specialty areas, and they may even do the same job at some hospitals.

If your child is at a children's hospital, he may have a child life specialist. A child life specialist helps meet hospitalized children's growth and developmental needs. This person also enhances their coping skills through play and other activities.

I do want to mention one more medical person before we leave this section. If, for whatever reason, you find yourself upset with your attending surgeon, one of the residents, a nurse, or any other worker, there is a person at most large hospitals whose job is to try to solve the problem. This person is known by various names: ombudsman, patient advocate, patient liaison, and other titles. This person's job is to listen to family members' anxieties, disappointments, or anger and to intercede on your behalf.

Parents have asked me: “How can someone paid by the hospital be my advocate?” All I can say is that this system works. Sometimes getting something off your chest helps the situation. It might help just to talk to someone not directly involved in your child’s care and whose job is to listen. I ask you to give the patient liaison a chance when you have a conflict. And if you have something nice to say about a doctor or nurse, that kind of feedback is valuable to them.

So that is the main “cast of characters” at the hospital. I have left out some of the medical people you will meet. But if you become familiar with those I have described, meeting the rest of the medical professionals will be easier.

Table 3.1**Medical Doctors: Education and Training**

Title	Degree	Board Qualification	Years of Training	Practices Independently
Medical student	Undergraduate	No	Years 3–4 of medical school	No
Intern	MD	No	Postgraduate year (PGY) 1	No
Resident	MD	No	PGY 2–4	No
Chief resident	MD	No	PGY 5+	No
Fellow or specialty chief resident	MD	Yes: adult general surgery	PGY 6+	No
Attending/consultant surgeon	MD	Yes: general and pediatric surgery	Training complete	Yes

Table 3.2**Nurses and Other Health Care Personnel: Education and Training**

Title	Years of Training	Degree	Practices Independently
Licensed practical (vocational) nurse (LPN)	2	No	No
Registered nurse (RN)	2 3	No BSN	No
Nurse practitioner (NP)	3 (BSN) 2 (NP)	MSN NP certificate	Yes, some states
Case manager	3+	BSN or MSN	No
Social worker	2	MSW	Yes, some states
Physician assistant	Varies	Associate, bachelor's, or master's	Varies by state

BSN indicates Bachelor of Science in Nursing; MSN, Master of Science in Nursing; and MSW, Master of Social Work.

Chapter 4

What Are the Diagnostic Imaging Tests?

Many diagnostic tests done before and after an operation involve imaging. In this chapter, I describe the imaging tests most often done in children. This chapter is brief because you will get a detailed explanation of these imaging techniques from either the doctor taking care of your child or the **radiologist**. This is the doctor in charge of the imaging equipment and the reading of the films produced.

Remember to sign a consent for a test only when you understand what the test is for and how it will be done. You have a right to look at the images these machines produce. However, they are complicated, so you'll need the radiologist to explain them to you. Surgeons and other physicians, especially cancer doctors (**oncologists**), often get quite good at reading films in their area of expertise. But they are not as trained in this as radiologists are. They also are not board certified/qualified in radiology.

Many hospitals now use computer screens to record images and do not produce films or photographs any more. These sophisticated digital systems enhance the medical images, making them more accurate and easier to read. Images can be "beamed" (sent by computer) to other places, for example, the operating room or a hospital in another city. Digital images are less expensive than film after the equipment is bought.

ULTRASOUND

Developed during World War II to detect enemy submarines, ultrasonography was first called sonar. Ultrasonography, also called ultrasound, is a system in which high-frequency sound waves enter the body. The sound waves bounce back at different rates from different tissues

Sophisticated digital systems enhance the medical images, making them more accurate and easier to read.

and organs. The “bounce” or echo is picked up on a screen and interpreted. The pictures are shadowy and require great skill in reading them. (Mine is basic!) Color called color Doppler can be added to ultrasound, so the flow of blood in and out of tissue can be seen and measured.

Ultrasound is a wonderful technique for seeing internal organs or structures in “real time” (as something actually happens). A common example is watching a fetus move inside the womb.

An ultrasound of the heart is called an **echocardiogram**. The brain also can be seen with ultrasound in a newborn. However, an older child’s skull is too thick for the sound waves to pass through.

X RAY

An **X ray** is an invisible beam of radiation that can penetrate the body, and when the X ray strikes a sensitive plate, a picture is formed.

X rays can be simple and fast, for example, a chest X ray. They also can be used for complicated diagnostic work, for instance, a barium swallow. In this test, the patient swallows a thick white liquid or sometimes food coated with barium. This substance can be seen on an X ray and can be followed down through the intestine. It makes the digestive system show up better on an X ray. A barium enema is used to study the large intestine, and the barium is put into the **rectum** (your child’s bottom). Many other substances besides barium can be seen as a contrast on X rays. They have different brand names, such as Hypaque.

Regular X rays are useful for studying bones. Doctors always use X rays in the diagnosis of a broken bone and to observe the bone’s healing within a cast. (X rays pass through a cast but not through bone.)

RADIONUCLIDE SCANNING

Radionuclide scanning is a technique in which a harmless radioactive substance called an isotope is injected into the body or swallowed. The body is then “scanned” inside a special machine that picks up the radioactivity and shows it on a screen. The isotopes are attracted to different parts of the body, so doctors can use this technique to learn about a specific organ’s function. For example, one kind of isotope targets the kidney. Another isotope goes to the cells that secrete stomach acid. Another goes to the thyroid, and so on. One isotope can see a specific cancerous tumor when it is tiny and cannot be seen any other way.

CT OR CAT SCANNING

CAT stands for computerized axial tomography. Never mind the big word. Most people know of this image as a CT or **CAT scan**. The scanner is a huge machine that the patient is put inside while lying down. It delivers multiple X ray beams in a circle around the body. A computer integrates thousands of images and builds a series of images of the body in sections, usually one centimeter apart, or about one fifth of an inch. You can see the inside of the body in great detail. The conventional way is to view the body with horizontal sections, but the computer can also reconstruct any of the areas of interest into three-dimensional pictures. This technique is useful for diagnosing and observing the size of tumors of multiple parts of the body. Doctors use it for lots of other conditions, too.

A big disadvantage of CT is that it delivers radiation to the body. So it is best to use CT sparingly, especially in children. Another disadvantage is that it does not perfectly show bones, blood vessels, or the brain and spinal cord.

MAGNETIC RESONANCE IMAGING

Magnetic resonance imaging (**MRI**) overcomes some of the disadvantages of CT. It does not use X rays. As far as we know, a patient can have MRI over and over again without harm.

The MRI machine was invented at the end of World War II. It did not get into medical use for decades after that, however.

MRI is a huge magnet. Remember in school putting iron filings near a magnet and watching them move to each end of the magnet? This is the principle of MRI. It creates a magnetic field all around the body. Everything in our body can be viewed as multiple tiny magnets. The many magnets in the patient's body line up under the influence of this magnetic field.

After a computer processes the image, the result is a remarkably clear picture of the inside of the body: brain, bones, spine, organs, and blood vessels. MRI can see whatever is there, normal and abnormal—even tumors. A new open MRI machine is being developed that can be used in the operating room in “real time” to help neurosurgeons look for a tumor deep in the brain.

A big disadvantage of MRI is that no metal can come near it. It also is very noisy and scary for kids, so they often need heavy sedation or even general anesthesia to have this test.

Both MRI and CT require the patient to stay still.

POSITRON EMISSION TOMOGRAPHY (PET)

PET scanning is a sophisticated form of radionuclide scanning, described earlier in this chapter. A radioactive chemical element called an isotope is attached to a substance that occurs naturally in the body, often glucose, which is the sugar in the blood. It is injected into a vein, and then the patient is placed in a large machine, which “reads” where the substance has gone. PET scanning is used to find abnormal areas, for example, where cancer is present. It can also measure abnormal function in a particular area. An example of this is that it can show abnormal heart muscle after a heart attack, next to normal muscle.

PET scanning is most useful in children with cancer, for whom it can assess the result of treatment (such as chemotherapy) on the tumor. The amount of glucose in a tissue shows up as a bright spot on the picture. Cancer uses more glucose than normal tissue, so it is much brighter than the surrounding area on a PET scan.

The use of PET scanning is quite limited now because of the size and expense of the machine. But I expect PET scanning will be much more useful in children as we gain in knowledge about the functions of different tissues.



PART 2

Please Listen to Us





Chapter 5

Are We the Only Parents Who Feel this Way?

My nephew's third child was born with a heart murmur. The doctors at the hospital where he was born made a tentative diagnosis of a not very serious condition. My nephew called me, and I suggested the baby have an **echocardiogram**.

The doctor treating the baby was reluctant to order this heart ultrasound test. The test involved a transfer to a nearby children's hospital. The doctor went so far as to tell my nephew and niece-in-law, "They are very busy there, you know. You wouldn't want your baby to have this test instead of someone who really needs it, would you?" Of course, my answer was "yes." I disagreed with the other doctor's diagnosis from what my nephew had told me. So my nephew insisted on the test.

It turned out the baby boy had a critical heart problem, which required an immediate operation. Had my nephew not insisted and instead agreed to the hospital's plan to send the baby home, the baby may well have died.

You probably do not have a relative who is a physician whom you can conveniently call for medical advice. So the message for parents is this: You must be satisfied that the doctors are covering all bases if the diagnosis of your child is not obvious. Make sure someone at a senior level is in charge of your child's care. Insist that this person talk to you as if you are intelligent, not just an anxious parent.



Before you go home, make sure you have the phone number of the doctor, nurse, or hospital floor.

DON'T BE INTIMIDATED

When you speak with the surgeon, don't be afraid to ask questions. Get the doctor to tell you the best- and worst-case scenarios. Ask: If the operation needed is major, what are the common complications? What are the chances that they will occur? What is the chance that the outcome of the operation will not be successful? See Appendix A for a list of questions to ask the surgeon.

Ask questions in the hospital, too. Most of the time you will receive detailed instructions on the care of your child at home. You'll need to know what to expect. If you aren't told, ask:

- What if your child doesn't want to eat, throws up, or has bad pain?
- What complications may occur late, and how will you recognize them?
- What restrictions in eating and physical activity are there? (When can he ride his bike will be your child's most important question!)

When you bring your child home from the hospital, it's likely that a question will come up that you forgot to ask or don't remember the answer to. Before you go home, make sure you have the phone number of the doctor, nurse, or hospital floor (or all three) that you can call when those questions arise. Don't be afraid to call the hospital, even if it is 3:00 am. Usually, the floor nurse can help you. If she can't, she can find someone who can.

“Our lives are suddenly turned upside down when we are told that our child needs an operation. At that point, it is not really relevant what the diagnosis is. We are stunned, terribly afraid, and have a million questions, most of which remain unasked in the shock of the moment. Who is this stranger who will operate on our child? How do we know she is qualified and skilled, will tell us the truth, and give us back our child well and happy? How do we know that she cares about our darling and about us?”

“When we cross the threshold of a hospital, we feel as if we are expected to drop our intelligence at the door. We have always been in control but now are intimidated by people telling us what to do. We are punished for being assertive. If we ask questions, we get the reputation for being pushy and no one comes near us. We suffer from lack of sleep and extreme anxiety. And the only familiar people around us, our family, are as scared as we are.”



Ask as often as you need to for an explanation you can follow.

Besides asking questions, it's important to listen. My nephew told me that he carried around a pen and pad of paper when his child was ill. He wrote down questions that he and his wife had, and the answers he got from the health care providers. In the hospital, he wrote down conversations doctors and nurses had about his son that he overheard. I thought this was very smart and something I had not thought of. You can learn a great deal by listening to a senior doctor or nurse teaching those junior to herself.

COMMON EXPERIENCES

During my more than 30 years of practice as a pediatric surgeon, I have spoken with many parents. The experience of having an ill child who needs a surgical procedure often causes the parents confusion and fear. The words in the box on the preceding page are a composite of what I heard from many parents.

Do all of these things happen to every set of parents? Of course not. But each of the examples is real enough that when parents get together and talk, common themes emerge. So let's discuss some of these concerns and ways to deal with these stressful situations.

TAKE YOUR TIME

Nothing but time is going to lessen the shock of hearing that your child needs an operation. You need a little time to deal with this, or you won't hear anything else the doctor says. This may take just a few minutes. Or you may need a separate session with the doctor later, when you can understand the explanation of the diagnosis and what surgical treatment the doctor recommends. You are entitled to this. If you need to come back or spend more time now, you must insist on it.

When you sign a consent for an operation, it is labeled “informed consent.” You must be sure, and your surgeon must be sure, that you feel fully informed about the risks and benefits of the operation. You must feel confident that this operation is right for your child and that this surgeon is the right person to do it.

DOCTOR, DON'T TALK JARGON

Medical jargon is the strange technical language that many health care providers use. Here is an example of jargon:

“Mrs. D., Jane has idiopathic thrombocytopenic purpura. She has not responded to the steroids, so she needs a splenectomy. Before a splenectomy, she'll have a Pneumovax injection. We'll do the splenectomy laparoscopically.”

Are you any wiser? Consider this explanation instead.

“Mrs. D., Jane has all those red spots on her skin and has some internal bleeding. This is a condition probably caused initially by a virus, in which little bits of tissue in the blood, called **platelets**, are not acting normally. Platelets prevent bleeding. When they are diseased, you see the little red spots called petechiae, and there may also be internal bleeding. The spleen is an organ in our body whose job is to mop up old and abnormal blood cells and parts of cells. Jane's spleen is overdoing it because her platelets are abnormal, and so the number of platelets in her blood is low. There is a vicious cycle here. The spleen is eating the platelets, and there aren't enough of them in the blood to act at all. The result is bleeding into the skin and sometimes other organs. The condition is known as idiopathic thrombocytopenic purpura. Idiopathic means it is of unknown cause. Thrombocytopenic is another word for low platelets. And purpura is bleeding.

“This condition can usually be helped by medications called steroids. Unfortunately, they have not helped Jane. So to avoid serious or dangerous bleeding, we recommend that we remove her spleen. The platelets can then increase in number, and they will usually gradually function normally. Because the spleen is also responsible for fighting certain kinds of infection,



we need to give Jane a vaccination to prevent those infections. We'll do this before taking out her spleen. We'll do the operation through tiny incisions called laparoscopy instead of a big one that would hurt more and take longer to heal.”

This is certainly a much lengthier explanation, but I hope you agree that it is easier to understand.

You are entitled to an explanation you can understand of what will happen to your child: medications, tests, and so on. If the surgeon explains something in jargon you don't understand or uses terms for parts of the body you don't recognize, say you don't understand. Ask as often as you need to for an explanation you can follow. See Appendix A for a sample list of questions for the surgeon.

Your silence means to the doctor that you understood. She may be so steeped in jargon that she simply does not understand she is speaking a different language from the one you are familiar with. Tell her.

A caution here. The less experienced the doctor, the more likely she is to use jargon. If you are at a hospital with junior residents or medical students, don't ask them what is going on. They won't knowingly mislead you, but if they don't know the answer to your question, they might get a little creative. Wait for the experienced residents, the chief resident, or the attending surgeon to ask your questions.

Try hard not to ask multiple people the same question. The multiple answers you receive may be hard to put together, and you'll end up being very confused. Instead, bring a piece of paper with you, and jot down your questions as they come up. Then refer to your list when the surgical team or attending surgeon stops by your child's hospital room. The surgeons will appreciate that you have thought out the questions ahead of time. It encourages them to give you concise answers. Don't forget to write down the answers! These suggestions are relevant when your child is in the hospital, but they apply equally if you are seeing the surgeon in the office or clinic.

IS THE SURGEON AN EXPERT?

Pediatric general surgery requires full training in general surgery and then two full years of training in children's surgery. The pediatric surgeon is trained to operate on the neck, chest, abdomen, and limbs. Usually a pediatric surgeon does not operate on the heart without additional training in heart surgery. A pediatric surgeon typically does not operate on the bones or the brain. An exception is in rural areas, where pediatric surgeons may need to do some of these procedures because of the absence of specialists.

In adult medicine, superspecialization has taken place. In a university medical center, you may find one surgeon doing nothing but breast surgery, another operating only on the liver, and so on. These surgeons become very experienced in doing these types of operations.

Because surgical problems are relatively uncommon in children, no one pediatric surgeon has experience with thousands of complicated operations. For example, I am known as an expert in esophageal surgery and replacement of the absent or injured esophagus in the child. The esophagus is the tube in which swallowed food goes down to the stomach. However, such esophageal conditions are rare in children. My total experience of replacing the esophagus is meager compared with some adult surgeons who have much experience with cancer of the esophagus. Does that mean my credentials are bogus? Not at all. Complicated operations, whatever part of the body they involve, require a set of general skills, good training, and meticulous attention to technical detail.

So the question "how many of these operations have you done?" will not necessarily give you a helpful answer.

Even a surgeon performing an operation for the first time can have a successful result if the surgeon is skilled. I once had a teenage patient who had had a major operation as a child. He had a complication and needed another operation. The type of operation I performed had never been done in a human before. I had done it in the laboratory and written about it but never performed it in a patient. The operation was a success. Years later the patient, now grown up, told me that I told him before the operation that it had not been done before in a human. This was truly informed consent! We are still friends, this patient and I. The operation has stood him in good stead, and I hear from him about once a year.

If a conflict with a doctor cannot be resolved, you have the right to change doctors.

Some surgeons claim they have done more of a certain procedure than anyone else in the world. Beware of such claims! Look at a surgeon's overall surgical experience, rather than the number of a certain procedure that she performs.

CONFLICTS

What do you do if you have an opinion about your child, and the nurses and doctors are not listening to you? You may hear phrases meant to be reassuring:

“I know best what to do for your child.”

“The opinion you've just expressed is not relevant in your case.”

“Let me be the doctor, and you be the parent.”

Or you may be treated as if you have not spoken.

Let me emphasize the following. You know your child better than any doctor can hope to. If you are convinced of your opinion, *stick to your position*, and insist that the doctor discuss it with you. You may be wrong, but you may be right.

I have never found it burdensome to listen to a parent's opinion. Sometimes parents have come up with good ideas I may not have thought of.

What do you do if you get into an argument with your doctor? First, it is better to avoid this if at all possible. Doctors need to understand the parents' anxiety, but they don't always do so. Parents need to understand that the doctor is rushed, often much too busy, and also worried about all her patients. Try to sit down with the doctor to talk—your nurse can often help with this—before your conflict turns into yelling at each other. Try to develop a cordial relationship with the doctor. In the end, your child will have less stress, you will have less stress, and your child will get better faster than if there is a conflict.

If you do have a conflict with a doctor or other care provider, a hospital often has an ombudsman or patient liaison, someone who is specially trained in handling awkward situations. Ask to speak to this person. This person will act as a liaison between you and the doctor and smooth out the difficulties.

If a conflict with a doctor cannot be resolved, you have the right to change doctors. The doctor also has the right to find you another doctor if the situation cannot be fixed.



Chapter 6

How Can I Be Part of My Child's Care?

STAY INVOLVED

Do become involved in your child's care. There is no reason that you can't bathe him, feed him, and read and sing to him. This will accomplish many things. Your nurse will be grateful, as you will free up some of her time, and she'll have more time to talk to you and answer your questions. Your child will be reassured that Mommy or Daddy has not abandoned him. You'll feel more in charge and less out of control, and the time will pass much more quickly.

NURSES ARE YOUR FRIENDS

Nurses may well have more time than doctors to answer questions, and they are present in the hospital unit all the time. Don't be afraid to come out of the room, or press the buzzer in the room to find your child's nurse. There is no rule that parents must be seen and not heard!

Nurses have the most complete information on your child. They will have varying degrees of knowledge about the surgical condition. But they will know the details of progress from hour to hour, which the doctors may not always be aware of. Moreover, they are at the bedside frequently. They will have much closer contact with you than the doctors and will be aware of your anxiety and stress.



*There is no rule that
parents must be seen and not heard!*

If you would like, you can see the details of care that the nurses record in your child's chart. In some hospitals the charts are all electronic. Since computers house all of the patients' records, don't hog these computers. There are never enough of them to go around!

WHAT TO TELL YOUR CHILD

You may be confused about how to interact with your child during an operation and hospital stay. Here are statements parents should say to their child:

- "I love you."
- "It's OK to cry."
- "It will hurt sometimes, but I will be there with you or waiting in your room."
- "You are getting better." (This one is critical. Older children know about death. If you don't reassure them, they may think that they are going to die.)
- "An operation is like magic that the doctor does to make you better. Anesthesia is a 'magic' sleep so that the operation will not hurt."
- "After an operation, pain medicine will make the hurt go away."
- "A kiss and a Band-Aid always make things better."
- "We'll have a special time—a bit like an extra birthday—when the operation is over."

I used to tell the child before the operation, "Moms and Dads feel sorry for kids when they have to have an operation, so they often buy them a present. You'd better be thinking about what you'd like!"

When a procedure is going to hurt, ask the child to say “Ouch” very loudly. By the time the child has done that, the pain will be over.

WHAT NOT TO TELL YOUR CHILD

There are certain things parents should not say when their child is in the hospital:

- “If you are not good, the doctor will come and give you a shot.” (Believe me, I have heard this one.)
- “It won’t hurt” when it will.
- “Before your operation, you will be put to sleep.” (A child may confuse this with a pet that was put to sleep.)

Likewise, parents should not do the following:

- Cry in front of your child or quarrel with the doctor. Kids get scared when they see this.
- Punish your child for being “bad” (“acting out,” throwing temper tantrums, kicking, biting, and so on). Instead, reward the child for being good after the fact.

OTHER THINGS TO KNOW

If you don’t want to be there when something painful is done to your child, especially if you will be upset by helping hold your child, then don’t. Always ask if it is possible and safe to give the child a sedative before a painful procedure. The nurses are usually advocates in this. Residents in a hurry may not want to wait for a sedative to take effect, and it isn’t always necessary or always safe. But ask anyway.

Don’t ask the doctor to remove her white lab coat. Instead, tell your son or daughter that the doctor will wear a white coat to keep her clean. Point out that she is not a scary person.



*“A kiss and a Band-Aid always
make things better.”*

Young siblings can say pretty gruesome things to each other about being “cut open,” “sticking needles in,” “shots,” and so on. Where do they learn it all? In general, however, children don’t understand about taking something out of the body that they are unaware of in the first place. The “magic” concept works well with small siblings, and you can keep the conversation general.

Just as it is important to be honest with the child needing an operation, it is important to be honest with your other children. They can be scared too. Their brother or sister is taken away to the hospital, and then Mommy and Daddy disappear too. Often the hospital you go to will allow siblings to visit. By visiting, they will know their brother or sister is getting better. Reinforce this, and repeat that their brother or sister will come home as soon as he or she is well.

What about discipline for a sick child? If you abandon your normal behavioral standards for your son or daughter, you will have a lot of difficulty after the child is well. A child is much happier and will scare less easily if he continues to have the same barriers and rules that he normally has. For example, if your child misbehaves and your normal action is to have him take a time-out, do the same. However, it’s not a good idea to spank a child who is being naughty. I hope you already avoid this ineffective method of discipline.

I hope that I have addressed the main problems and questions that parents of a sick child are likely to have. If you have questions not answered here, don’t hesitate to ask the doctors and nurses for help.

PART 3

Childhood Medical Problems that May Need an Operation





Chapter 7

Lumps and Bumps

It might be helpful to discuss some conditions in children that need surgical treatment. This list will not be complete because that would require a book of its own. This chapter and the other chapters in this section are for parents of children whose surgeon will be a general pediatric surgeon like me. This part may help you know which questions to ask about your child's surgical problem.

MOLES

A mole is a skin growth that is usually dark. Babies are not born with moles except in rare cases. Moles develop during childhood. Most people have at least several moles by the time they are adults.

Moles are almost always **benign** (noncancerous) in children before puberty. Unless moles are very large (more than half an inch in diameter) or change in appearance, you usually can ignore them. Signs of a benign mole are:

- Small (diameter smaller than a pencil eraser)
- Flat or slightly bumpy, often with hairs growing from it
- Unvarying color, usually dark brown to near black
- An evenly shaped border

Moles should be removed at some point if they are located on the palms of the hands, soles of the feet, or in areas of irritation, such as the belt line, future bra line, or genital area.

Unless moles are very large or change in appearance, you usually can ignore them.

HEMANGIOMAS

A hemangioma is a collection of small blood vessels in or below the skin (subcutaneous), often staining the skin bright red. A hemangioma usually becomes visible within the first few weeks of life and goes away by itself after about two years of age.

If the hemangioma is below the skin and does not have the typical skin stain, the doctor may not be sure of the diagnosis and may suggest its surgical removal. Large hemangiomas or those near the eyes, nose, or genital area also may need removal surgically. A surgeon with a special interest in hemangiomas should look at them. This physician may be a pediatric surgeon or a plastic surgeon.

CYSTS

A cyst is a piece of tissue rolled up in a ball, usually containing fluid or tissue debris or both. There are many types of cysts. I will describe a few types here.

Sebaceous cysts and dermoid cysts

Sebaceous and dermoid cysts describe a cyst containing old skin, which is cheesy in appearance. Sebaceous cysts have a small connection, which reaches the skin surface. They can therefore get infected by germs, which come from the skin into the cyst. Once this happens, they are a frightful nuisance and can get reinfected. So it is better to remove them before this happens.

Dermoids are similar cysts but without the communication with the surface, so they don't get infected. They may occur in the scalp area and often grow at the outside edge of the eyebrow or in the midline of the neck. They are removed, usually because the doctor cannot be sure of the diagnosis. Eyebrow dermoids are obvious but can get very large and ugly. Of course, if they are allowed to grow, they will require a bigger incision to remove.

Congenital cysts

Congenital conditions are present at birth or before birth. Two types of congenital cysts are thyroglossal duct cysts and branchial cleft cysts.

Thyroglossal duct cyst: what a mouthful! Most medical terms are long. But they can be broken down for better understanding. Ask your doctor to do this for you. Let's break this one down into its parts:

- thyro* = something to do with the thyroid, a gland in the neck
- glossal* = something to do with the tongue
- duct* = a hollow passageway or tube
- cyst* = a piece of tissue rolled up in a ball and usually containing fluid or tissue debris or both

So, a thyroglossal duct cyst is a swelling along a hollow tube that runs between the tongue and the thyroid gland. Since the thyroglossal duct communicates with the inside of the mouth at the back of the tongue, germs can get in and cause an infection. This is a mess and is hard to remove completely. Therefore, this kind of cyst usually is removed as soon as it is diagnosed. It appears as a lump in the middle of the neck near the Adam's apple and moves upward if you can get your child to stick his tongue out at you!

Most often, swollen lymph glands decrease to their normal size when the infection is over.

Branchial cleft cyst

This cyst is a remnant of a process that occurred in your baby almost before you knew you were pregnant. In the developing neck, fissures appear, called branchial clefts that are open to the outside and the inside of the throat, a bit like the gills of a fish. Neck organs are developed from these areas, and usually the neck closes up after this process is finished.

Occasionally an opening between the throat and the side of the neck persists, and saliva can dribble out onto the neck from a tiny pinhole. This is usually thick and gooeey, like your saliva gets when you go to the dentist. There may or may not be a cyst or lump associated with the pinhole. It may be just a little tract from inside to outside.

Germs from inside the mouth or throat can get trapped and cause an infection. So it is better to remove the tract or cyst before infection happens.

There are literally hundreds of other lumps and bumps that can occur in the skin, beneath the skin, in the muscle, and so on. The general principle here is simple. Lumps and bumps belong in a jar and not under the skin, especially when your doctor cannot be sure what they are.

SWOLLEN LYMPH GLANDS

We have **lymph glands** all over the body. They are an important part of the immune system, acting as a barrier to the spread of illness. Enlargement may indicate a problem. Common places where lymph glands get enlarged are the sides of the neck, the armpits, and the groin. Usually they swell because of an infection, for example, in the throat or ear. Most often, swollen lymph glands decrease to their normal size when the infection is over. If they continue to grow or persist at an enlarged size, your doctor may recommend their removal.

HERNIAS

A hernia is a protrusion of a loop or knuckle of an organ or tissue through an opening, which may be a normal part of the body or may be abnormal. I will discuss three kinds of hernia: **umbilical**, **inguinal**, and **incisional**. There are other types, but they are not common.

Umbilical hernia

An umbilical hernia is a bulge that occurs at the umbilicus, or belly button. Sometimes children call it a “biblical” hernia because of the difficulty of pronouncing um-bil-i-cal. It occurs shortly after birth after the umbilical cord drops off. It consists of a bulge in the skin and a separation of the underlying tissue. You can poke your finger through the defect into the child’s belly, rather like poking your finger into the finger of a glove and turning it outside in. Umbilical hernias can reach a very large size, and they tend to grow during the first year of life. They are very common in dark-skinned children. Why, I don’t know.

Sometimes an umbilical hernia can assume a shape that looks like a penis. The other shape that is troublesome is a large round hernia resembling a breast. Parents have told me that the child may try to suck on this. These two shapes of umbilical hernia need to be repaired surgically when diagnosed. For other types of umbilical hernia, there is no hurry to operate.

These hernias rarely get stuck (**incarcerated**), although there are exceptions when the skin is large and the underlying defect is small. Also, many of these hernias close by themselves. The rule doctors generally go by is this: most hernias with a defect smaller than two centimeters—a bit smaller than an inch—when the child is two years of age will close by the time the child is five years old.

The operation is simple. A curving “smiley” incision is made below the belly button. The surgeon separates the skin from the underlying tissue and stitches the firm edges of the defect together horizontally. The middle stitch catches the inside of the extra skin, to recreate the belly button. Extra skin usually is left in place. This skin will shrink as the child grows, just like the stretched skin of the pregnant mother goes back to normal after her baby is born.

Hernias never disappear by themselves.

Inguinal hernia

The first thing to do is to forget about Grandpa's "rupture." Kiddy hernias are different from those in adults. Adults often have a "direct" hernia that is a weakness in the back wall of the groin so that the hernia bulges directly through this wall. Children rarely get direct hernias. Instead, they have a congenital (present from birth), *indirect* hernia.

Here is how an inguinal hernia develops. Think of a glove, very thin and made of latex rubber like the doctors and dentists use. In your imagination, tie off all except the index (pointer) and little fingers. If you don't have a good imagination, do it on a real rubber glove. Now turn the glove inside out, blow into it, and hold it up with the two fingers hanging down. The hand part of the glove is the belly, or **abdomen**, lined by a membrane called the **peritoneum**. The two fingers are the processes that extend down into the groin through an opening in the muscle called the "internal ring."

During development, the sex organs (ovaries for girls, testes for boys) begin near the kidneys, which are situated in the upper part of our "glove" on each side and behind the glove. As the baby develops, these organs follow two finger-like projections, like the fingers of our glove. The ovaries stop (most of the time) in the pelvis and don't come out through the internal ring into the groin. The testes do, and they descend down into the scrotum.

What is supposed to happen during the last three months of pregnancy is that the two finger-like projections shrivel up and disappear. This seals off the inside of the abdomen from the groin at the level of the internal ring. Remember, that's the natural hole in the muscle. An indirect hernia results when this process does not finish.

One or both projections (which we'll call a hernia) can stay open completely from the abdomen to the scrotum. They may close partially. If the top part stays open, this is called a hernia. If the bottom part stays open, it is called a hydrocele—literally a water sac. A hydrocele can occur with a hernia or by itself. The **intestine** in the abdomen can then slip out into the hernia and appear as a bulge, either just into the groin or travel all the way into the scrotum.

How surgeons fix this type of hernia is to complete the process that nature forgot to do. We separate the hernia from the adjacent tissue (the blood vessels to the testes in the boys; in the girls there isn't much tissue at all). Then we stitch it closed at the internal ring, where it was supposed to have closed itself. The incision is made in the skin crease in the groin and gets covered with hair when your child grows up.

A word about hydroceles. If there isn't a hernia, a lot of these will disappear by themselves by the time the child is two years of age. Hernias never disappear by themselves, and there is no medicine to change that.

So, you say, Grandpa never had his hernia operated on. He just lived with it. Here's the difference: the hernia in a young child or infant may get stuck out. In other words, the intestine slips into the hernia and can't get back where it belongs in the belly. If the hernia gets stuck in the groin (we call this incarceration), an experienced doctor must push it back in and operate on it soon afterward.

If the doctor cannot "reduce" the hernia by pushing it in, she must operate on it immediately. The reason for this is that the intestine can cut off its own blood supply on the sharp edge of the internal ring and die, a condition known as **strangulation**. Your baby or child will be very distressed and in pain if the hernia is incarcerated, so don't delay going to your doctor or the hospital emergency room.

The development of the sex organs is a simpler process in the girl, because the ovaries don't go all the way down and don't take as long to drop. Therefore, hernias are less common in girls than in boys, but they do occur.



Incisional hernia

A breakdown of deep tissue covering muscle in the area of a previous stomach operation is called an **incisional hernia**. Children, as well as adults, may get an incisional hernia soon after an abdominal operation or years later. It feels like a bulge under the skin. An incisional hernia also can become strangulated, although this is fairly rare. Usually, these hernias are unsightly, and the surrounding muscle may not work properly if the hernia is large. Therefore, an operation usually is recommended.

Chapter 8

Abdominal Conditions

The **abdomen**, or belly, is the part of the body that goes from the diaphragm (pronounced di-uh-fram)—the big breathing muscle that separates the chest—down to the pelvis. The pelvis is the lower part of the body and is protected by the hip bones. The abdomen contains lots of solid and hollow organs. Your doctor will have a picture of these.

The largest solid organ is the liver. It takes up all of the right upper area of the abdomen and sits under the lower right ribs. Except in a small infant, and when it is diseased, the liver cannot be felt from the outside. It processes food substances; makes proteins, especially blood clotting factors; and processes old blood, which is broken down and formed into **bile**. This bile collects in the gallbladder and empties into the intestine to aid in digestion. The liver also processes many drugs.

The spleen is another solid organ under the ribs, in the left upper part of the abdomen. It is responsible for fighting infection and also breaks down blood cells when they get old.

Also in the left upper part of the abdomen is the stomach, which starts the process of food digestion. This empties food into the duodenum, the first part of the **small intestine**, where pancreatic juice and bile are added. The duodenum curves in a big “C” across the middle of the abdomen.

Nestled in this curve is the **pancreas**, which adds digestive enzymes to the food as it goes to the duodenum. The pancreas also makes insulin to control blood sugar. The duodenum then becomes the jejunum. Here, more digestive juices are added, and the digestive process is mostly complete.

The next part is the ileum, where digestion finishes and food absorbs into the body. The jejunum and ileum together are called the **small intestine**, or small bowel. The ileum empties whatever is left into the **large intestine**, which extracts all the water and makes the stools. The large intestine travels from the right lower part of the abdomen, up the right side, across the

The abdomen is a very busy place, and lots can go wrong.

abdomen above the belly button, and down the left side. It empties into the rectum and out through the anus. So the large intestine looks like a picture frame with the lowest part of the square missing, and the small intestine sits in the area of the “picture.”

Behind all these organs, tucked under the ribs, are the two kidneys. They cleanse the blood and make urine. Urine runs down paired tubes called ureters into the bladder, which sits in the pelvis. The bladder stores urine until you are ready to go to the bathroom. Above the kidneys are the adrenal glands, which make steroids and other hormones.

The other solid organ in the female abdomen is the pair of ovaries and the uterus, or womb. They are in the lower part of the abdomen.

The abdomen is a very busy place, and lots can go wrong. I will concentrate on the intestine for this brief description of common conditions. Again, this chapter is not meant to be a substitute for a conversation with your doctor. Rather, it is a way for you to become somewhat familiar with some of the terms your doctor may use, so you know what questions to ask.

APPENDICITIS

Appendicitis is very common. The appendix is at the beginning of the large intestine hanging off the cecum. The cecum is the enlarged portion of the first part of the large intestine. Since the appendix is a narrow tube and is attached to the cecum, stool can get inside it. Usually the stool comes in and out and is eliminated, but for some reason a bit of stool may get stuck.

Intestinal viruses, which are common, especially in the child, may cause swelling of lymph tissue nearby. The intestine does not have lymph glands in it, but it does have patches of lymph tissue, called Peyer’s patches, in the wall of the intestine, and so does the appendix. We’ll come back to Peyer’s patches in the next section.

So let's say a virus comes along, causes swelling of lymph tissue in the wall of the appendix. A bit of stool is in the appendix at the time, and it cannot get out because the exit is swollen shut. There are lots of bacteria or germs in the stool, and they begin to grow and infect the appendix. Early on, the appendix gets red and inflamed, and then pus appears.

The appendix can rupture, or burst. Once the appendix ruptures, a serious infection occurs. Parents should bring their kids to the hospital or doctor when they first get stomach pain, before the appendix ruptures.

INTUSSUSCEPTION

Intussusception is a serious condition that occurs usually in infants under one year of age. It is one portion of the intestine sliding into another.

Here is what happens. Along comes an intestinal virus, which may not cause any symptoms at all. The lymph patches, or Peyer's patches, which are attached to the bowel wall, swell up in the small intestine just a few inches before the small intestine enters into the large intestine. The side of the intestine is not tiny like the appendix, so it does not get swollen shut. But, the intestine "senses" the swelling, "thinks" it is a piece of stool, and works to move it along. This movement is called **peristalsis**. Normally it serves to move food from one end to the other.

As peristalsis moves the patch along, the wall of the intestine gets tucked inside and becomes telescoped. Think of a long balloon. Put your fist into one end and move it into the balloon. Your fist "telescopes" the balloon inside itself. This is what happens to the intestine.

The Peyer's patch can really move far in this telescoping process, and sometimes it will go into the large intestine for quite some distance. This condition is known as intussusception, literally "sliding inside."

In the early stages of this condition, the baby cries and draws his legs up onto his tummy in pain. This pain is colicky. The baby initially has episodes of pain, then he'll calm down for a while. Later the blood supply to the telescoped intestine gets shut off, and the baby may pass bloody mucus in the stool. Later still, that part of the intestine dies, and this is very dangerous.

*Once the appendix ruptures,
a serious infection occurs.*

Early on, the telescoped bowel can be pushed back by introducing air into the rectum and watching it by **ultrasound** or on **X ray** with barium (a white liquid that can be seen on X ray). If this procedure is not successful, the baby must have an operation.

INTESTINAL OBSTRUCTION

An **intestinal obstruction** is a blockage of the bowel (intestine). The most common cause of this condition is internal scarring, or **adhesions**, from a previous operation. It also results from growths inside or outside the intestine, both benign and malignant.

A dangerous form of intestinal obstruction is midgut **volvulus** (twisting) caused by **malrotation** (incorrect positioning of the intestine early in pregnancy).

Midgut volvulus

Between the eighth and 12th weeks of pregnancy, the intestine of the developing baby, known as an embryo at this stage, grows very quickly in length. The abdominal cavity does not grow quickly enough, so out comes the entire small intestine, the jejunum, and the ileum, into the umbilical cord. It may seem weird, but that's what happens. It goes back into the embryo as the cavity grows bigger. Most of the time the intestine gets back into the right place.

Remember our earlier image of the large intestine occupying three sides, like that of a square picture frame, with the small intestine taking up the space in the middle? Normally the upper part, the duodenum just after the stomach, gets attached by filmy tissue to the back wall of the abdomen into a C curve. The lower part, the cecum, gets attached to the right lower abdomen.

Sometimes (for reasons we don't understand) the intestine goes back the wrong way. The filmy tissue still develops, but it attaches these parts in the *wrong place*. They become close together in the middle of the abdomen so that the beginning and end are too close together. This means that all the blood vessels that keep the intestine alive are bunched together in a narrow stalk. A twist of the intestine can occur that is very dangerous. It usually occurs early, in the first week or two after birth, but it can occur at any time during life. A malrotation (literally bad or incorrect rotation) is the underlying condition, and the volvulus is the twist that can occur at any time.

A volvulus produces blockage—intestinal obstruction—and cuts off the blood supply to the intestine. If the blockage is not treated immediately, the intestine will die. This situation is a life-threatening emergency. It is important to recognize the symptoms. The baby will vomit green bile. The belly will not be bloated. The baby will fuss and be in pain. Later the infant may have a bloody stool and then be very ill.

A wonderful operation called the Ladd procedure corrects the condition and saves the child's life. William Ladd, believed to be the first pediatric surgeon in the United States, invented the procedure. In the operation, the filmy tissue is cut and the intestine is rearranged so that the volvulus cannot happen again. This procedure cannot rearrange the intestine in the way that nature failed to do. The appendix ends up on the left side of the abdomen (normally it's on the right). This would make the diagnosis of appendicitis very difficult. So the appendix is always removed in this procedure.

OVARIAN TORSION

Torsion is a twist, like volvulus, but when an ovary twists, it is called ovarian torsion. The ovary is the internal female sex organ. Inside the ovary, growths can occur. A growth makes the ovary larger than normal. This enlarged organ can then twist. The pain is often mistaken for appendicitis, particularly when the right ovary is twisted.

The most common ovarian growth, a teratoma, is usually benign. Ovarian masses such as a teratoma can be huge, making the girl and mom think she's getting fat or, in teenagers, pregnant. Treatment is to try to remove the mass, leaving behind some ovary when the blood supply is still good.

In boys, testes twist also. However, it is much more obvious because the testes are outside the body.

BLEEDING IN THE BOWEL

Before we leave the abdomen, I'll briefly mention bleeding in the bowel. There are many causes for this; most are very uncommon. Stomach ulcers, for instance, are rare in children. Rectal bleeding, however, is fairly common. It is usually caused by a fissure or crack in the skin around the anus. Kids, even babies, can get this, especially after a bout of constipation. It usually heals itself, with stool softeners to relieve the constipation.

Bright red bleeding from the rectum may be caused by a polyp, a type of protruding growth in the intestine. Polyps can occur anywhere in the large intestine. Rarely, they occur in the jejunum, ileum, or stomach.

Polyps in adults can mean cancer. They rarely do in children. So if your doctor tells you your child has a polyp, either feels it in the rectum or discovers it after a barium enema, don't panic. Most polyps will twist themselves off and come out in the stool.

Sometimes polyps may need to be removed through a **sigmoidoscope** or **colonoscope**. A sigmoidoscope is a short instrument that can be inserted into the rectum. A colonoscope is a long instrument, through which the entire large intestine can be examined. The polyp is usually a red, round ball, looking a bit like a cherry on a stalk. There may be a number of polyps.

There is another cause of rectal bleeding I'll mention: Meckel's diverticulum. This is a little finger-like projection hanging off the main intestine, a remnant of a process in the embryo that did not disappear before the baby was born. These little sacs communicate with the small intestine about a foot from its end and can contain cells identical to those

lining the stomach. These cells put out acid just as they would if they were in the stomach. The acid can cause a small ulcer in the adjacent tissue, which then bleeds. The blood can be bright red or purplish. There can be a lot of blood, but the condition causes no pain.

There is a test for Meckel's diverticulum. A radioactive material is injected into a **vein**; it goes into the extra stomach tissue and lights up on a special screen. This test requires a skilled radiologist to interpret.

Treatment is surgical. The offending diverticulum, which has no use whatsoever, is removed.



Chapter 9

Chest Conditions

Chest conditions are much less common in children than in adults. Before you can understand what can go wrong in the chest, it is helpful to understand the structures of the chest.

STRUCTURES OF THE CHEST

The chest is the part of the body surrounded by the ribs, which run from the spine at the back to the breastbone, or sternum, at the front. The chest contains the heart and the great vessels. These vessels include the aorta, which carries blood from the heart to the body, and the two **venae cavae**, which collect the blood and return it to the heart. Also among the great vessels are the pulmonary arteries, which carry the blood to the lungs to pick up oxygen, and the pulmonary veins, which carry the blood from the lungs back to the heart.

The lungs also sit inside the chest in their own space, called the pleural cavity. They absorb oxygen from the air and breathe out the carbon dioxide our body makes.

There are other things in the chest also. The trachea (windpipe) and bronchi are the hollow tubes that carry air in and out. The thymus, a large mass of lymph tissue, lies just behind the breastbone. The heart, trachea, bronchi, and thymus are in the middle part of the chest, called the mediastinum. Through this part also runs the esophagus, the tube that carries food from the back of the throat to the stomach.

WHAT CAN GO WRONG

Tumors—benign and malignant (see Chapter 11)—cysts, infections, and other conditions can occur in the chest structures.



Of course, kids can breathe in or swallow objects that can get stuck in the trachea, bronchi, or esophagus and that may require surgical removal. Don't give peanuts to a child under five years of age!

Most conditions in the chest, as a rule, are diagnosed by means of X rays.

Chapter 10

Newborn Conditions

Babies can be born with cysts and tumors in various places. Symptoms will depend on where they are. Newborns also can have developmental abnormalities, parts of the body that did not develop properly in the mother's womb. This chapter describes a few such birth defects.

If your baby has a birth defect, you will want to get more information about it elsewhere. A good source of information about birth defects is the March of Dimes (www.marchofdimes.org).

Sometimes congenital conditions can be diagnosed surgically before birth. If so, parents have time to adjust, find out all about their baby's condition, and learn ahead of time what treatment will need to be done.

ATRESIAS

Sometimes babies are born with parts of the intestine missing. An atresia is the absence of the normal continuity of the intestine.

An example is a baby born with an interruption in the esophagus. In this condition the esophagus is in two pieces, and the lower half is connected to the trachea or breathing tube. This is known as esophageal atresia, which means absent development of the esophagus, with a tracheoesophageal fistula, an abnormal connection between the trachea and the esophagus. Warning signs of this type of atresia are drooling, often with coughing and choking upon feeding.

Atresias can occur anywhere along the length of the intestine. Duodenal atresia, jejunal, ileal, colonic, and anal atresia mean blockage of the intestinal parts mentioned (duodenum, jejunum, and so on). Sometimes an actual part of the intestine is missing with two blind ends in all the parts as mentioned above.

All atresias are treated surgically. They can be complicated to repair, especially because some of them occur with kidney, heart, or other problems.

OMPHALOCELE AND GASTROSCHISIS

Remember the developing intestine coming outside the body (described in Chapter 8)? Sometimes the intestine doesn't get back in and stays on the outside of the body. When it protrudes from the belly button and is covered with a membrane, it is called omphalocele. If there is no membrane and it comes through the abdominal wall near the belly button, it is called gastroschisis.

The treatment of either of these defects is an operation, which puts the intestine back where it belongs. It may require several stages.

CONGENITAL DIAPHRAGMATIC HERNIA

About one in 5,000 infants are born with a hole in the diaphragm (the big breathing muscle separating the chest from the abdomen). The chest on the same side as the hole often is filled with the baby's intestine. This condition is known as congenital diaphragmatic hernia. It is much more common on the left side and is somewhat more common in boys than girls. These infants also have poorly developed lungs and usually have breathing problems from birth.

This condition is a life-threatening illness. It needs an operation as soon as possible to close the hole and move the intestine back to the stomach.

Chapter 11

Tumors

Tumors can be benign or malignant (cancerous). This chapter will mention only one benign tumor and then discuss a few types of cancer. Fortunately, cancer is rare in children.

BENIGN TUMORS

Benign tumors can occur anywhere in the body. One type of benign tumor occurs in the kidney and is called a mesoblastic nephroma. (Nephroma means kidney tumor.) It is not malignant, almost never recurs, and that's the end of it when it is removed. It causes panic initially, however, because it mimics a common kidney cancer.

Surgical removal of a benign tumor usually is simple unless the tumor is in a strategic spot, such as wrapped around nerves.

CANCEROUS TUMORS

Cancer is not a single disease but rather a group of diseases. Childhood cancers are not the same as adult cancers.

The principle of cancer is universal, however. Cancer involves the uncontrolled growth of certain cells. The cancer cell has escaped from the normal systems in the body that control its growth and where the cell belongs in the body. For example, you won't find liver cells anywhere but in the liver, but you might find liver cancer cells in many different places. The spread of cancer to other parts of the body is called **metastasis**.

Now to the differences between childhood and adult cancers. Cancer of the colon is a fairly common adult cancer that is very rare in children. When it occurs in a child, usually an adolescent, it is often much more aggressive than in the adult.

Some cancers develop in children but not adults. A cancer of childhood called a neuroblastoma (more on this later in this chapter) rarely occurs in adults.

The most common childhood cancer is leukemia, which is cancer of the blood cells. A surgeon plays a very minor role in treatment of leukemia. The surgeon may perform a **biopsy** of a lymph node, which is rarely needed for diagnosis. Or a surgeon may place a tube called a **catheter**—such as a **Port-A-Cath** or **Broviac** catheter—for long-term chemotherapy.

I will mention three other malignant childhood tumors, which do involve the surgeon in treatment. Wilms' tumor is a malignant tumor found in the kidney. Hepatoblastoma is a childhood liver cancer. Neuroblastoma is a cancerous tumor that originates from part of the nerve system called a ganglion. It can occur in the neck, chest, or abdomen. It can also start in the adrenal glands that sit above the kidneys. This cancer spreads across and around lots of vital structures such as blood vessels. Wilms' tumor and hepatoblastoma also can grow and spread (metastasize) to other parts of the body.

These three cancers can occur at any age in childhood, although they are more common in younger children. They can grow large before they are detected. This is particularly true of liver and kidney tumors, because most of the liver and the kidneys are hidden under the ribs.

Each type of cancer is different, both in how it looks under the microscope and in how it behaves in the body. If your child has cancer, you need to speak extensively with the cancer specialists (surgeon and **oncologist**) about that particular cancer.

It is important for children with cancer to be treated by pediatric oncologists and other pediatric specialists, because children's cancers are so different from adult cancers. The treatment of childhood cancer is always being refined, resulting in much improved survival for most types of childhood cancers.

Treatment

Most childhood cancers, including the three I just named, are treated with a combination of remedies. Surgical treatment is usually first. For example, if a tumor is discovered in a kidney, the tumor will be removed at the initial operation if possible. (The kidney needs to be removed also.) Then chemotherapy will be used to treat any cancer cells that might have escaped from the kidney.

If the tumor is too large to remove safely, the surgeon will perform a **biopsy**. A piece of the tumor will be taken out and looked at under a microscope, to make sure it is cancer. Chemotherapy will then shrink the tumor, and it will be removed later. The patient also may receive **radiation treatment**, depending on the extent and the cell type of the tumor.

The regimen (course of treatment) of biopsy, chemotherapy, plus or minus radiation, then an operation is pretty routine for neuroblastoma as well.

Liver tumors will have a biopsy first as a rule. Then chemotherapy will be given to shrink them, followed by surgical removal.

Points to remember

- Childhood cancers are different from adult cancers.
- Many of them can be cured.
- Treatment is with different regimens, often an operation and chemotherapy and sometimes radiation alone or all three types of treatment.
- The same cancer can behave differently in different people.



Chapter 12

Conclusion

I hope that this book has given you some insight into the complex world of children's surgery. As I wrote in the beginning, it is not meant to be comprehensive book but a guide to the new and scary situation you find yourself in when your child needs an operation. If it has taken some of the mystery out of the hospital and made you less intimidated by the people you meet there, I have done my job.

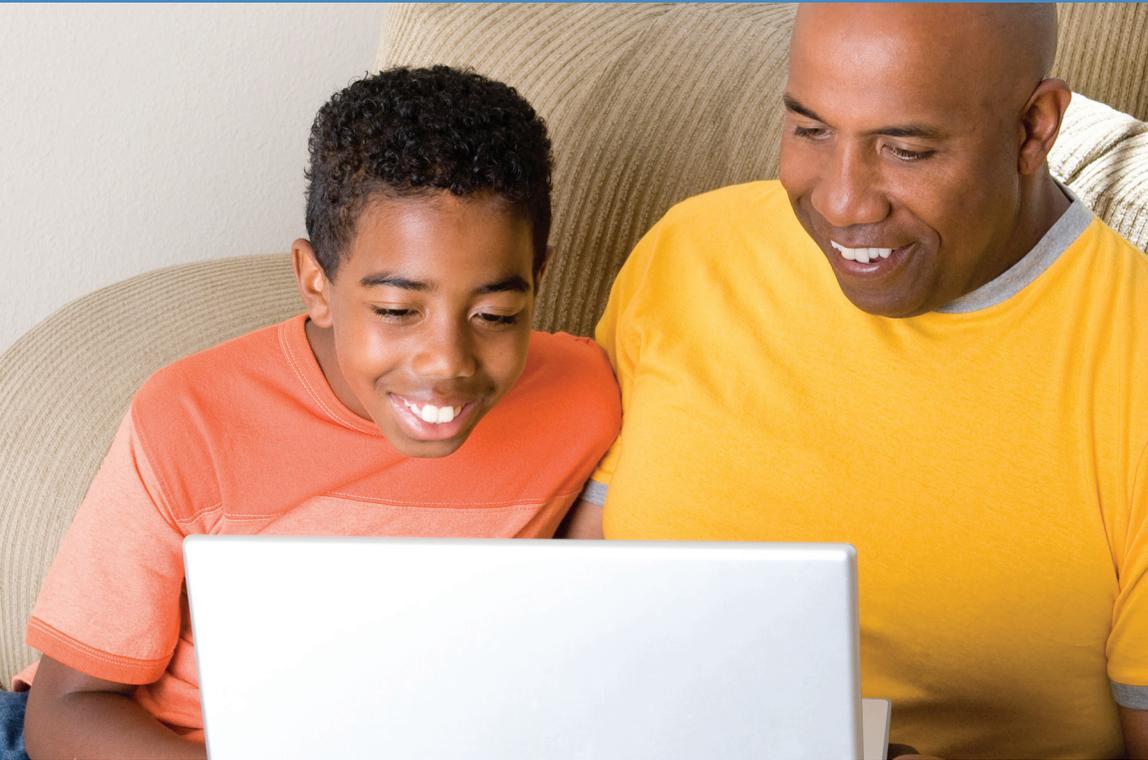
One of the greatest joys of my life has been to hear from parents over the years as their children have grown up and to hear from former patients. I have been invited to graduations, weddings, and even taken care of some of my former patients' own children. One of the things I have said to parents over and over again is: "Some day, this will all be a bad dream." Perhaps this book makes it a little less like a nightmare.

When I was President of the American College of Surgeons—the first woman to hold that position—my theme for my presidential year was humanity. I chose that theme in an effort to remind surgeons why they joined the medical profession in the first place. I sincerely hope that if and when you need a surgeon for your child, you will encounter a surgeon who is the best technically but who also is one who understands your needs as well as those of your child.



PART 4

More Information





Appendix A

Questions to Ask Your Surgeon about the Operation

1. What is your training and experience in children's surgery?
2. Are you board certified in pediatric surgery?
3. Are you a member of the American College of Surgeons?
4. Are there any options besides an operation?
5. What will happen if my child does not have this operation?
6. What is the name of the operation?
7. Where will you perform the operation: the hospital, a surgical center, your office?
8. Will my child need to stay in the hospital? If so, how long?
9. How will you do the operation? Please explain the steps.
10. Where will the incision be, and how long will it be?
11. What do you expect the outcome to be?
12. What are the chances that the condition will recur and need another operation?
13. What are the complications of this kind of surgical procedure? How likely are they to occur?
14. What is the worst that can happen?
15. What pain medicine will my child receive?



16. What restrictions will my child have after the operation? Are they temporary or permanent?
17. What are the long-term effects, if any, of the operation?
18. How often will we return for postoperative visits?
19. Will my child need any special care at home after the operation?
20. Does this condition run in families? If so, how likely are my other children to need this same operation?

Appendix B

Resources

MEDICAL ASSOCIATIONS

Medical associations that have reliable public health information about surgery and children's health include the following:

- American Academy of Pediatrics (*www.aap.org*)
- American College of Surgeons (*www.facs.org*)

Both these Web sites have online information as well as links to other useful Internet sites.

WHAT IS A PEDIATRIC SURGEON?

This public information brochure is available on the American College of Surgeons Web site at http://www.facs.org/public_info/yourhealth/pedsurg.pdf. Or order your free copy by calling 312/202-5391.

THE INTERNET

I cannot end this book without a brief discussion of the Internet. Chances are you have a computer at home or access to one. Your child may be better at it than you are! The Internet has a lot of medical information. Use it to see if there is any information about your child's problem and the operation he or she will have.

Also, look up your chosen hospital's Web site. Most medical centers have a Web site with information about the hospital and hospital procedures.



Do remember, though, that the Internet is unregulated. You can get misleading or even inaccurate information from some Web sites. If you use the Internet, discuss the information you read there with your doctor before and after your child's operation.

Glossary

abdomen

Belly.

adhesions

Internal scars that cause organs or tissues to stick together. May cause blockage of the bowel soon after or often years after an abdominal operation.

advanced practice nurse

Usually has a master's degree in nursing or higher and may be specialized to give care to certain patients, such as patients with cancer. See also registered nurse.

analgesia

The relief of pain. The agent that relieves pain is called an analgesic.

anesthesia

Use of a substance (gas, injection, paste, or liquid) to remove sensitivity to pain. There are several types. See entries for caudal anesthesia, general anesthesia, local anesthesia, regional anesthesia, and spinal anesthesia.

appendix

A small, narrow, hollow organ, attached to the cecum (see large intestine). It has no useful function in humans and often gets infected, leading to appendicitis.

attending

A board-qualified or board-certified physician.

benign

Noncancerous. Describes a tumor that does not spread to other parts of the body but grows locally. Small benign tumors usually are removed with an excisional biopsy (see biopsy). Larger benign tumors can interfere with other areas but do not always need to be completely removed.

bile

A yellow or green liquid made in the liver from blood components. It is stored in the gallbladder, then is emptied into the part of the intestine just beyond the stomach through a small tube called the common duct. After surgical removal of the gallbladder (such as for gallstones), the bile goes directly from the liver to the intestine. Bile aids in the digestion of food.

biopsy

A sampling of tissue from an abnormal area. The tissue sample (called a biopsy specimen) is examined under the microscope with special stains to diagnose a condition. The biopsy may be “incisional,” in which only a small piece of tissue is taken. Or it may be “excisional,” in which the entire abnormal area is removed. A lump under the skin is removed with an excisional biopsy.

boards

Examinations that test knowledge in specialties of medicine. The American Council of Graduate Medical Education (ACGME) nationally administers these exams.

bowel

See intestine.

Broviac catheter

A tube made of rubber-like material called silicone that is inserted into a large vein near the shoulder and left in place. It is used when a child needs chemotherapy or total parenteral nutrition (see TPN). The end of the catheter is left outside the body and taped to the skin. It usually has two ports (openings). One port is used for drawing blood, and the other is used for giving chemotherapy.

case manager

An advanced practice nurse with a master’s degree who organizes and coordinates care, both inpatient and outpatient care. May be in a specialty, such as surgery or orthopedics, or for a particular diagnosis, such as cancer or cystic fibrosis.

CAT scan, CT scan

Literally “computerized axial tomography.” A huge machine that takes multiple X rays through the body at short intervals. A computer then integrates these X rays to give great images of the body, bones, internal organs, or brain. A special computer program can make the images three-dimensional. Used extensively for diagnosis and to observe disease, such as cancerous tumors, during treatment.

catheter

A tube that comes in various sizes and is used to inject fluids or medicines, and to remove blood and other body fluids.

caudal anesthesia

Injection of local anesthetic (or morphine for pain control after the operation) into the cavity in the back below the spinal cord. It numbs all the nerves in the pelvis and groin. A type of regional anesthesia, it often supplements general anesthesia (see entries for general and regional anesthesia). Also called caudal block.

cecum

See large intestine.

charge nurse

The nurse leader on the inpatient floor who is responsible for overall care, planning, staffing, and minute-to-minute operations. Usually this nurse is very experienced but has no direct patient care assignment.

chemotherapy

Multiple medicines used to treat cancer and occasionally other diseases. May be called simply “chemo.”

clinical care coordinator

An experienced nurse who performs specific functions in an inpatient setting, such as quality assurance, discharge planning, or liaison with insurance companies.

colon

Part of the large intestine. See large intestine.

colonoscope

A long instrument with a lighted telescope, through which the entire colon can be examined.

complete blood cell count

Measures levels of red blood cells; hemoglobin, the red pigment in blood that carries oxygen to the tissues; white blood cells; and platelets.

congenital

A condition present at birth or before birth.

critical care unit

See intensive care unit.

differential diagnosis

A list of possible diagnoses to explain symptoms.

differential white blood cell count

A count of all the types of white cells in the blood. May indicate infection if abnormal.

duodenum

See small intestine.

echocardiogram

Ultrasonogram (ultrasound image) of the heart. Shows shadows of the heart chambers, valves, and major blood vessels. With the addition of color, it shows the direction of blood flow in all parts of the heart.

elective surgery

An operation not needed right away but scheduled at a convenient time for the surgeon and the patient. For instance, it may be scheduled during a school break.

emergency surgery

An operation that must be done soon after symptoms of an acute (not chronic) condition begin. Usually it is within hours of a diagnosis.

enteric

To do with the bowel or intestine, especially the small intestine. For example, enteric feeding is nutrition by mouth or by tube into some part of the bowel.

ER, emergency room

The area in the hospital where emergency conditions are first treated. Also called emergency department or ED.

failure of an organ or tissue

Usually means decreased or absent function of an organ or tissue. Examples: In heart failure, the heart does not pump strongly enough; in kidney failure, the kidney does not make enough urine or any urine; in liver failure, the liver is diseased and does not process digestion products properly. Organ failure is not necessarily irreversible.

fistula

An abnormal opening between organs or from an organ to the skin. Examples: anal fistula, an opening in the skin near the anus, resulting from infection; tracheoesophageal fistula, a newborn condition in which the trachea (windpipe) is connected to the esophagus (food pipe).

gallbladder

A sac attached to the liver, which stores bile before emptying it into the intestine. May develop stones.

gastrostomy

A tube inserted directly into the stomach in the left upper part of the abdomen. This is usually used when the patient needs prolonged drainage or direct feeding into the stomach.

general anesthesia

Patient is asleep. Major operations usually are done this way. It often is started with an intravenous (IV) drug and then maintained with a gas. The patient breathes through a mask or tube. Children who fear needles may receive “laughing gas” (nitrous oxide) to begin with. Then an IV line is started for fluids after the child is asleep.

hemoglobin

Pigment that makes the blood red. It carries oxygen from the lungs to all parts of the body. It is bright red when fully oxygenated—at full oxygen capacity. It gradually turns blue as it gives up its oxygen to the tissues. Arteries are red. Capillaries, which are small vessels in the skin and organs, are pink. Veins are blue.

hernia

See incisional hernia, inguinal hernia, and umbilical hernia.

ileum

See small intestine.

incarcerated

When tissue or part of an organ gets stuck outside of where it should be. The best example is when a loop of bowel comes out into a hernia and will not easily go back into the belly. A surgical emergency. See also strangulated.

incision

A cut made in the skin and tissues to perform a surgical procedure.

incisional hernia

A breakdown of deep tissue covering muscle in the area of a previous operation. The scar bulges and the edges of the separated tissue can usually be felt through the skin.

induction

Usually refers to the initial process of anesthesia. May also be used for the first treatment with cancer medicines, as in chemotherapy induction.

inguinal hernia

Hernia occurring in the groin (inguinal region), the area between the top of the thigh and the lowest part of the abdomen.

injection

A shot of medicine or fluids into the body by a needle or needle system. See entries for intravenous (IV), intramuscular, thecal, and subcutaneous.

intensive care unit

A special unit of the hospital that is self-contained and separate from the regular hospital rooms, where patients receive close monitoring and extra care. Usually there is one nurse per child.

intensivist

Doctor specially trained to take care of critically ill patients in the hospital who coordinates care with the child's surgeon and primary care doctor. Often this doctor is a pediatrician (internist in adult medicine) or anesthesiologist.

intern

Physician in the first postgraduate year of training. Has graduated from medical school and has an MD. Also known as PGY-1, postgraduate year one.

intestine

Also called bowel and gut. See entries for small intestine and large intestine.



intestinal obstruction

Blockage of the intestine. The most common cause is adhesions, or internal scarring from a previous operation. May be caused by any condition that blocks the intestine from inside the intestine or outside. Symptoms include cramps, stomach pain, bloating, and vomiting.

intramuscular

Literally, inside a muscle. May refer to an injection into a muscle or to describe the location of something abnormal. Example: an intramuscular mass.

intravenous (IV)

A way of putting fluids into a vein, usually with a small plastic tube or catheter. Used for rehydration and to give fluids when the patient cannot drink liquids. Medicines also can be given by this route.

jejunum

See small intestine.

keyhole surgery

See minimally invasive surgery.

laparoscopy

See minimally invasive surgery.

large intestine (also called colon)

The first part of the bowel is slightly bigger than the rest and is called the cecum. The appendix hangs off the cecum. The rest of the large intestine is responsible for absorbing water and making stools. Also includes the sigmoid colon, rectum, and anal canal.

licensed practical nurse (LPN), licensed vocational nurse (LVN)

A person licensed by the state to do certain basic levels of patient care. Does not do care planning and cannot give medications. Reports to a registered nurse.

local anesthesia

Numbing of a small area of skin and tissue under the skin so that a painless cut can be made. Can be applied to the skin as a paste or shot. The injection hurts a little as the needle goes in, then numbs the area of injection. It lasts from 30 minutes to about two hours depending on the numbing medicine used. Often used for minor outpatient procedures, although less often in young children.

lymph gland, lymph node

A swelling of tissue in the lymphatic system, a lymph gland traps tumors and infections. Often enlarges with infection, for example, in the throat, ear, or eye. The lymphatic system, also called lymphatics, is a system of colorless vessels running throughout the body. The lymphatics gather up tissue fluids and return them through larger channels to a vein in the neck.

lymphoma

A malignant tumor of the lymph nodes, usually treated with chemotherapy.

lymph node

See lymph gland.

magnetic resonance imaging

See MRI.

malignant

A cancerous tumor that has the capacity to grow outside of the place it began and spread to other parts of the body by direct growth, bloodstream, or lymphatics. May need an operation, chemotherapy, radiation treatment, or a combination of these treatments to control the cancer and try for a cure. There are many types of malignant tumors, and each one is different. Example: thyroid cancer usually is cured more easily than brain cancer.

malrotation

Occurs in the midgut (small intestine), which did not undergo correct positioning in the embryo very early in pregnancy. The whole small intestine hangs off a narrow stalk, which contains all the blood supply. This can twist and cut off the blood supply, a dangerous condition known as volvulus.

medical student

Person who after college attends medical school. Spends the first two years of medical school in classes and laboratories and the last two years on clinical rotations in hospitals. The medical degree (MD) is awarded on graduation.

metastasis

A spread of a tumor from one part of the body to another. The plural is metastases. The verb is metastasize.

minimally invasive surgery

A technique in which a surgeon does a deep surgical procedure by passing long-handled instruments through several tiny incisions. A video of the inside of the body, taken by a camera inserted into the body, enlarges the surgical area and allows the surgeon to see what she is doing. Laparoscopy is an operation in the abdomen; thoracoscopy, a surgical procedure in the chest.

MRI

Magnetic resonance imaging. A technique that shows images of the internal parts of the body. Does not use X rays. The machine is a huge magnet that acts on the millions of magnets in the human body, lining them up. A computer interprets these images and presents them as an internal image of the body. Particularly good technique for imaging bones, tumors, and the brain and spinal cord.

nasogastric tube

Tube that is inserted through the nose into the stomach to drain stomach juices after an abdominal operation when it is used.

NPO

Latin abbreviation for “nothing by mouth.” This order is given when the stomach must be empty, such as before an operation with general anesthesia.

nurse manager

A nurse assigned to a particular hospital floor. May be a single person or more than one. Duties include clinical care oversight and care plans (called clinical nurse manager), operations and staffing (operations nurse manager), and education of nurses (education nurse manager).

nurse practitioner

See pediatric nurse practitioner.

occupational therapist

Person trained to help patients acquire or reacquire life skills, such as feeding, dressing, and bathing.

oncology

The study of cancer.

oncologist

A doctor who specializes in the treatment of cancer.

operating room (OR)

The room in which an operation is performed.

PCA

Patient-controlled analgesia. An intravenous device that allows the patient or parent to push a button and release pain medications into the bloodstream. The dose is carefully calculated, and there is a “lockout” mechanism on the machine so the patient cannot overdose.

pancreas

A solid organ in the mid-upper abdomen. It makes enzymes to digest food, which empty through a duct, a hollow tube, into the duodenum (see intestine). It also makes insulin, which controls blood sugar.

patient-controlled analgesia

See PCA.

pediatric nurse practitioner (PNP)

An advanced practice nurse with a master's degree and special training in pediatric practice. Can practice in an inpatient setting, outpatient setting, or both. Often functions as a physician extender. This varies from state to state, from full independence to practicing with a physician.

peristalsis

Movement of the intestine from the top (esophagus) to bottom (anus) that propels food and stool successively from one end to the other.

peritoneum

Thin membrane lining the abdomen and covering all the internal organs.

PET scanning

Positron emission tomography. A technique that shows images of the body functioning at the level of the cells or the internal working of the cells. Used mostly in adults. Currently it can be useful in children to follow treatment of tumors.

PGY

Postgraduate year. Denotes year of training after the medical degree is obtained.

physical therapist

Person trained in rehabilitation. Teaches walking with crutches and retrains muscles that have lost function from an operation or trauma. Usually deals more often with children with chronic problems.

physician assistant (PA)

A person licensed by the state to perform the functions of a physician extender. This person is not a nurse so does not have the breadth of medical knowledge of a nurse. Practices under the supervision of a physician.

platelets

Small pieces of tissue that are made in the bone marrow and circulate in the blood. They are responsible for plugging holes in blood vessels to stop bleeding. Can be increased or decreased in different disease states.

Port-A-Cath

An intravenous device that is inserted surgically into a large vein in the shoulder or neck to give strong medications (see chemotherapy) or nutrition (see total parenteral nutrition) or to draw blood for tests. It has a small chamber that sits under the skin just below the collarbone. A special needle is used to enter this chamber. Between treatments the needle is withdrawn, and the child can get the area wet.

positron emission tomography

See PET scanning.

postanesthesia care unit

See recovery room.

radiation treatment

Strong X ray beams are directed at the area to be treated, such as a cancerous tumor. Specially trained doctors use sophisticated methods of outlining the tumor, gauging its size, and deciding how much radiation is needed to shrink the tumor. May be used in combination with chemotherapy and an operation.

radiologist

Doctor who is in charge of the equipment used for imaging diagnostic tests, such as ultrasound, X ray, CT, MRI, and PET. Also reads the images produced. Radiology is a medical specialty and requires years of study after medical school.

recovery room

Also called postanesthesia care unit (PACU). The place where the patient spends about an hour to awaken from anesthesia. Your child will have a special nurse for this time.

red blood cell (RBC)

The cell in the bloodstream that carries the hemoglobin. It gives the blood its red color. Also called erythrocyte.

red blood cell count

Total number of red blood cells in one milliliter of blood (0.03 ounces).

rectum

See large intestine.

regional anesthesia

Injection of a local anesthetic into the nerves supplying the area to be numbed. It takes longer to act than a local anesthetic but lasts longer. Used when a larger area needs numbing.

registered nurse

Person who is trained to plan and give patient care. May be trained in a two-year school and hold a diploma or may have a bachelor's or master's degree in nursing. Is licensed by the state, which develops and monitors standards. See also entries for advanced practice nurse, clinical care coordinator, case manager, and pediatric nurse practitioner.

resident

Postmedical school trainee in different medical specialties. Each specialty has a specified training period. Also known as PGY or postgraduate year 1, 2, 3, and so on.

respirator

Also called ventilator. A machine that takes over breathing when a patient cannot breathe on his own or if the work of breathing is so great that it takes all the patient's energy. The machine pumps oxygen into the lungs through a breathing tube, called an endotracheal tube, in the trachea, or windpipe. The respirator then allows air to passively come out of the lungs. It can be triggered by the patient or set to do all the work itself.

respiratory therapist

Person who is licensed to deal with airways and breathing machines. Works with the nurses and physicians but cannot practice alone and cannot give intravenous medications. Can give inhalant medications with a physician order. Seen in an intensive care unit where patients are on breathing machines.

rule out

Exclusion of a diagnosis. For example, “rule out appendicitis” means it is not clear if the patient has appendicitis. The rule out label disappears once the doctor makes the diagnosis.

sedative

Medication that makes a patient calm, often sleepy. Procedures can be performed under sedation without agitating or hurting the child, who will not remember having anything done.

sigmoidoscope

A short metal tube with a light, through which the rectum can be examined.

small intestine

Bowel from the duodenum, right after the stomach, as far as the large intestine. Includes duodenum, which begins at the end of the stomach; jejunum, where digestion begins; and ileum, where digestion finishes and absorption of food substances occurs.

social worker

Person with a master's degree who acts as the “switchboard” for family needs of the patient in the hospital. May be assigned by diagnosis, location in the hospital, or patient's age (when not in a children's hospital).

spinal anesthesia

Injection of local anesthesia (or morphine for pain control) into the back between the bones of the spine. May be used alone with the patient awake or sedated, or to supplement general anesthesia. It is a very safe way of giving an anesthetic. It is wonderful for pain control after an operation; in this case, the tube used to administer the anesthetic may be left in for a few days.

strangulated

See also incarcerated. A piece of tissue or part of an organ that has become stuck in a place it doesn't belong, for example a hernia, and has lost its blood supply and died. A surgical emergency.

subcutaneous

Immediately under the skin.

thoracoscopy

See minimally invasive surgery.

total parenteral nutrition (TPN)

A way of supplying all the calories a patient needs for complete nutrition when he or she cannot eat or cannot eat enough by mouth. Given through a vein.

triage

Process of deciding how urgent a condition is and how immediate treatment needs to be.

tumor

This word comes from the Latin root for swelling—in other words, a lump. It is most used to describe an abnormal growth, which may be benign or malignant.

ultrasound

A machine that generates sound waves that are bounced off internal organs and that project onto a screen as shadows. These can be used to check normal and diseased organs. Adding color (Doppler) flow to the ultrasound gives information about blood flow into and out of an organ.

umbilical hernia

Hernia occurring at the belly button.

veins

Blood vessels that carry the blood back to the heart. They contain blood without much oxygen and therefore look blue.

venae cavae

Two large veins into which smaller veins empty. They return blood to the heart from the upper body, superior vena cava, and the lower body, inferior vena cava.

ventilator

See respirator.

volvulus

Twisting of an organ. Can be any organ that is not sealed in its position. A rare but dangerous condition. Can occur in the stomach, intestine, spleen, kidney, or more often in the ovary or testes. In this last case, it is called torsion.

white blood cell (WBC)

Blood cell that is part of the body's immune (infection and cancer fighting) system. Also called leukocyte. There are several kinds of WBC. Neutrophils increase in number when a bacterial infection is present. Lymphocytes usually increase in the presence of nonbacterial (viral or fungal) infections.

white blood cell count

Total count of the white blood cells in one milliliter (0.03 ounces) of blood. Often broken down into the types of white blood cells.

X ray

An invisible beam of energy that goes through flesh and produces images on a special screen.



About the author

Before **Kathryn D. Anderson**, MD, FACS, became the first woman President of the American College of Surgeons in 2005–2006, she spent 32 years as a pediatric surgeon in Washington, DC, and Los Angeles, CA. During the course of her career, Dr. Anderson treated many young patients and helped their parents understand not only the conditions her patients had that required an operation but also how to navigate the complex system that is a medical center. Dr. Anderson's goal in writing this book was to help take away some of the helplessness and fear that parents feel when they hear the word surgery related to their child. Dr. Anderson shares her experience as a surgeon who has dealt with many children and their families over the years in order to help parents deal with the pain of learning how to deal with a situation they do not welcome in the first place.

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