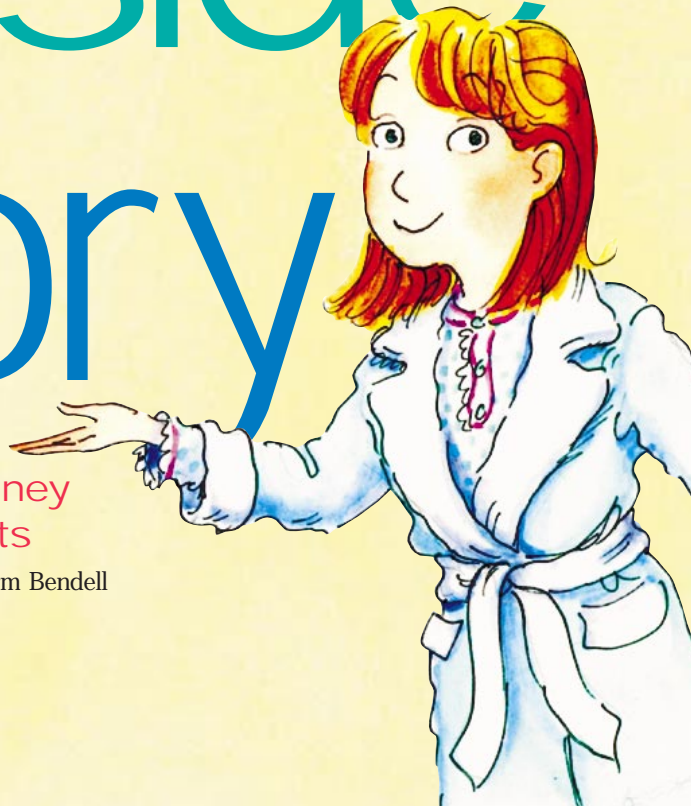
 Fujisawa Healthcare, Inc.



The Inside Story



A Kid's Guide to Kidney
and Liver Transplants

By Karen Crowe • Illustrated by Norm Bendell

This book belongs to:



Your Signature Here

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Thank you to all the transplant patients, family members, and technical advisers who shared their experiences and expertise to make this book a great resource to those who need it.

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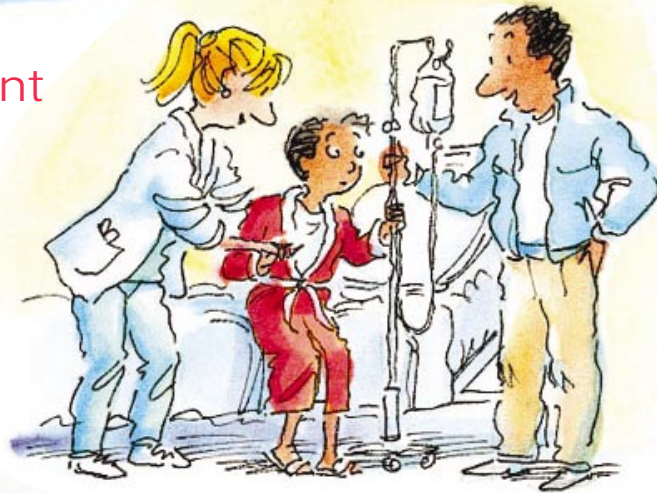


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Dear Reader,

This book was written especially for you—one of the thousands of kids around the world whose kidneys or liver are not working properly. Your doctor says an organ transplant can help. Each year, hundreds of kids in the U.S. get organ transplants of *all* different kinds—this book focuses on kidney and liver.

There's more to a transplant than having an operation. This book will fill you in on the things you'll need to do *before* and *after* your surgery to help make your transplant a success. You'll also meet lots of kids on these pages who know what you're going through—they've been there, too. These kids were once seriously ill but are now strong and healthy, thanks to their transplant. They've shared their experiences and advice, hoping to make *your* transplant easier.

You can read this book from beginning to end, or flip through it to read about certain topics at certain times. We hope it will answer your questions and help you feel more comfortable and confident during your transplant experience.

Best wishes for a bright and healthy future!

Your Friends at Fujisawa Healthcare



“When I found out I needed a transplant, I felt bad because I didn’t want to go through all of that. But I also felt good because I wanted to get off dialysis. I wanted to eat ice cream and sleep over at friends’ houses—things I couldn’t do before my transplant.”

Douglas B.

Age 9, 3 months after kidney transplant



“I wondered about the transplant a lot when I was in bed at night. Mostly, I wondered when my organ would come. It was frustrating. It made me angry and a little scared.”

Abby P.H.

Age 14, 3 1/2 years after liver transplant



“My wait for a new liver was the longest 6 months of my life. I was nervous, but I knew this was the only way to get better. I was also excited that I would be normal, life would be normal, everything would be normal!”

Hayden W.

Age 12, 5 weeks after liver transplant



“I wanted a stereo to take to the hospital when I had my transplant, so I baked cinnamon bread (my special recipe—without salt) and sold it to neighbors to earn money for the stereo. It gave me something to work towards, and helped keep my mind off the waiting.”

Katy M.

Age 14, 3 years after liver transplant



“I felt scared as I was waiting for the transplant, but I am really happy that I have it now.”

Anabel L.

Age 12, 5 years after 2nd kidney transplant



“My advice is: don’t be afraid to get a transplant. You’ll feel better than you do now. After you recover, you won’t be in pain, you won’t be in the hospital, and you’ll have more fun because you’ll be able to do a lot more.”

Jamal B.

Age 13, 8 years after kidney transplant

Before Your Transplant

You probably have lots of questions about getting a transplant. This chapter explains what you can expect before your surgery and ways to prepare for that all-important day.



Getting the News

How are you handling the news that you need a transplant? Here's some advice to get you through this tough time.

Mixed Emotions

These kids tell how they felt when they got the news.



"I felt scared, but I was also really interested in learning more about transplant surgery and why I needed it."

Ben Z.

Age 13, 6 years after liver transplant



"I tried not to think about it very much. I guess I was in denial and waiting for some sort of a miracle."

Kate S.

Age 16, 4 years after kidney transplant



"I felt strong and so good playing sports that I didn't understand why I needed a transplant. My parents said, 'If your kidney fails completely, you won't feel good anymore.' After that, I was set on having surgery."

Jeanna J.

Age 16, 1 1/2 years after kidney transplant



A Flood of Feelings

An organ transplant is a complicated procedure. There's so much to learn that you may feel overwhelmed at first. But kids often feel better when they know what to expect. So the more you learn, the less stressful your experience is likely to be—and the speedier your recovery. Two good reasons to find out as much as you can about your transplant!

When you first found out that your kidney or liver needed to be replaced, you may have felt afraid about what lay ahead. Or maybe you were angry that your body was causing you so much trouble. Maybe you didn't believe you were sick enough to need a transplant, or were relieved that surgery would help you feel well again. Or maybe you were shocked, and unable to think at all. These are all normal reactions. In fact, often kids feel many of these emotions at the same time.

Talking about It

It's natural for you to feel worried—*everyone* getting a transplant does. (Even grownups.) It's OK to cry. And if you don't want to hear details about your surgery right away, that's OK, too.

But talking about your fears and hopes can calm your nerves and prepare you for the challenges ahead. So when you *are* ready, share your feelings with family, friends, or members of your transplant (medical) team, who are trained to help. People can't read your mind, though; it's up to you to let them know your thoughts.

The Road to Recovery

Your transplant journey will not be easy, but other kids have gone down this road before and say it's worth it. Here are some tips to help you along the way:

- Take one day at a time. Don't worry about what will happen in a few weeks or months.
- Control the things you can (like your diet, exercise, and taking your medicines), and leave the rest to your doctors and nurses.
- Try to stay positive. You don't have to be cheerful or brave *all* the time—after all, transplants are tough. But when you keep your hopes high, your body has more energy to heal itself.
- Make the most of each day: laugh and do things you enjoy. Look forward to the future.



Your Kidneys & Liver

What Do Kidneys Do?

Your kidneys have 3 main jobs:

- They wash your blood, cleaning out whatever is not needed, including extra water. (These “waste products” are carried out of your body in urine.)
- They produce a chemical your body needs to make red blood cells. (These cells carry oxygen that’s needed throughout your body.)
- They produce vitamin D; it helps keep bones healthy.

What Causes the Kidneys to Fail?

The most common reason young people need kidney transplants is that they were born with a defect that keeps their kidneys from working properly. But your kidneys can also stop working due to an infection, injury, or diseases like kidney stones (saltlike crystals that form in kidneys and prevent them from draining).

Symptoms of Kidney Failure

Often people don’t feel any symptoms when their kidneys first begin to fail. But as their condition worsens, they may:

- tire quickly
- bruise easily
- feel sick to their stomach
- not produce much urine
- have swelling in their legs, ankles, hands, and around their eyes
- have high blood pressure
- feel itchy

What Does the Liver Do?

Your liver is one of the largest organs in your body. No wonder it’s so big—it has many important jobs:

- It makes *bile* (a thick yellow fluid your intestines use to digest food).
- It stores iron, vitamins, minerals, fats, and sugars until your body needs them.
- It produces natural chemicals to help your blood clot.
- It removes substances from your blood that could harm your body.

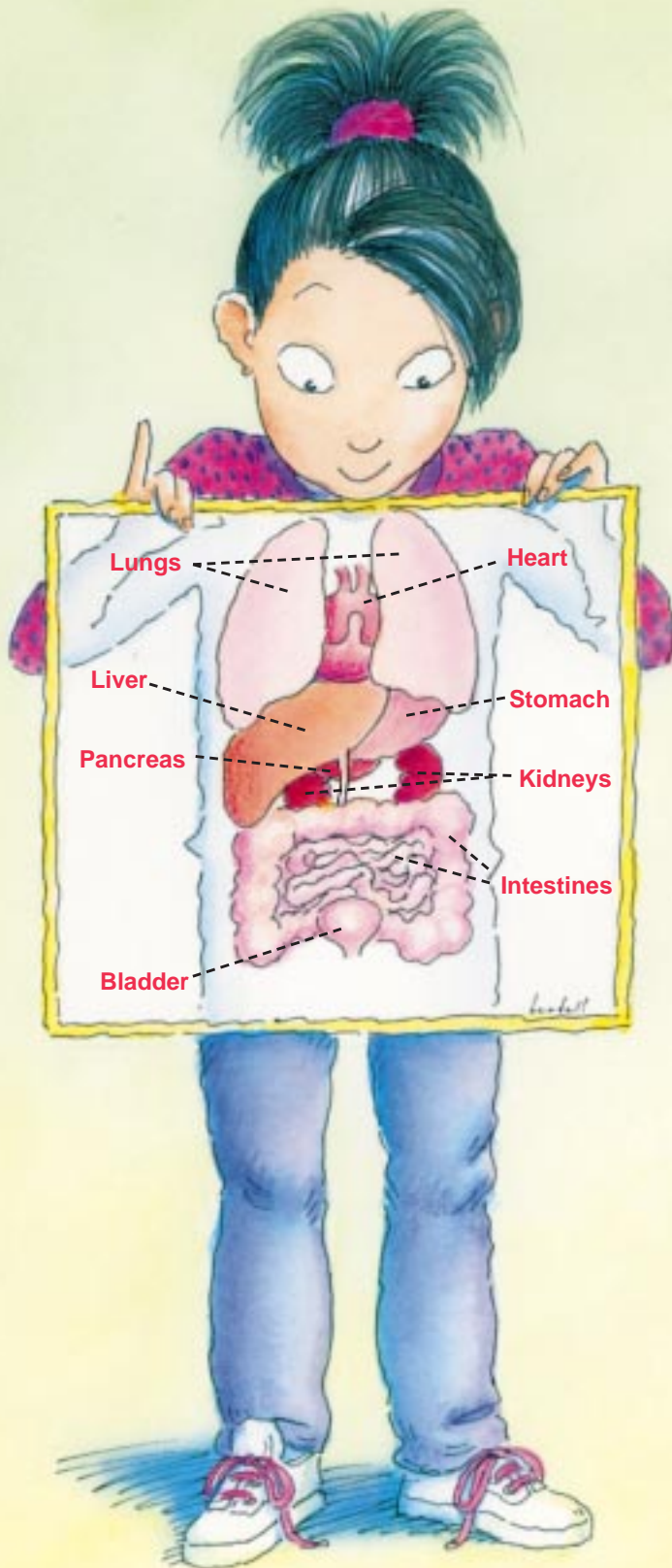
What Causes the Liver to Fail?

Your liver is a strong organ. In fact, it’s able to heal itself after most serious illnesses. But sometimes the organ becomes so damaged from an illness or a defect that it can no longer do its job. The most common reason kids need a liver transplant is that they have blocked or missing *bile ducts* (the tubes that drain bile from the liver to the intestines).

Symptoms of Liver Failure

When your liver stops working properly, you may experience these symptoms:

- *jaundice* (yellowing skin or eyes caused by a build-up of bile in the blood)
- very itchy skin
- dark-colored urine
- confusion
- bruising easily
- nosebleeds or other bleeding that won’t stop
- swollen belly
- tiring easily
- vomiting blood



A Description of Kidney Dialysis

Many people with kidney failure undergo *dialysis* for months, or even years, before getting a transplant. When receiving dialysis, you are connected to a manmade kidney—a machine that removes waste products from your blood. While on dialysis, you must also watch your diet. Although dialysis will clean your blood, it can't do the other important jobs that kidneys do, such as making the natural chemicals that keep your bones strong and your blood healthy. The only thing that can do that for you is a kidney transplant.



Transplant Basics

Now you know your body will work—and feel—better with a healthy kidney or liver. Here are other questions you may have.



What's going to happen to me?

When your kidneys or liver stop working, you become ill. For some kids, that means struggling to stay awake in school or having to sit out of gym class. Other kids might spend weeks or even months in the hospital, too sick to leave. In order for your body to work properly, you need to get a “replacement part.” Doctors will perform an operation to replace your unhealthy organ with a healthy one. (Pages 20-21 describe transplant surgery in more detail.)

Where will the healthy organ come from?

A living person may be able to donate an organ to you. A “living donor” is either a *blood relative* (someone related to you by birth, such as a parent, grandparent, sister, brother, aunt, or uncle), or a *nonblood relative* (a stepparent, adoptive parent, or even a close family friend). Not just anyone can donate an organ to you. He or she must be in good health and have certain things in common with you medically. (Page 14 describes these things and explains how a matching organ is found.)

If a living donor can't be found, doctors will hope to use an organ from someone who had a serious injury or illness and did not survive. (The family of this person offers their loved one's organs to help people like you who need a transplant.) The organ must be a good match and healthy, just as a living donor's would need to be.



“My donor, Mrs. Skut, was a friend of our family, and she's the nurse at my school. She was so nice to do that for me!”

Erik P.

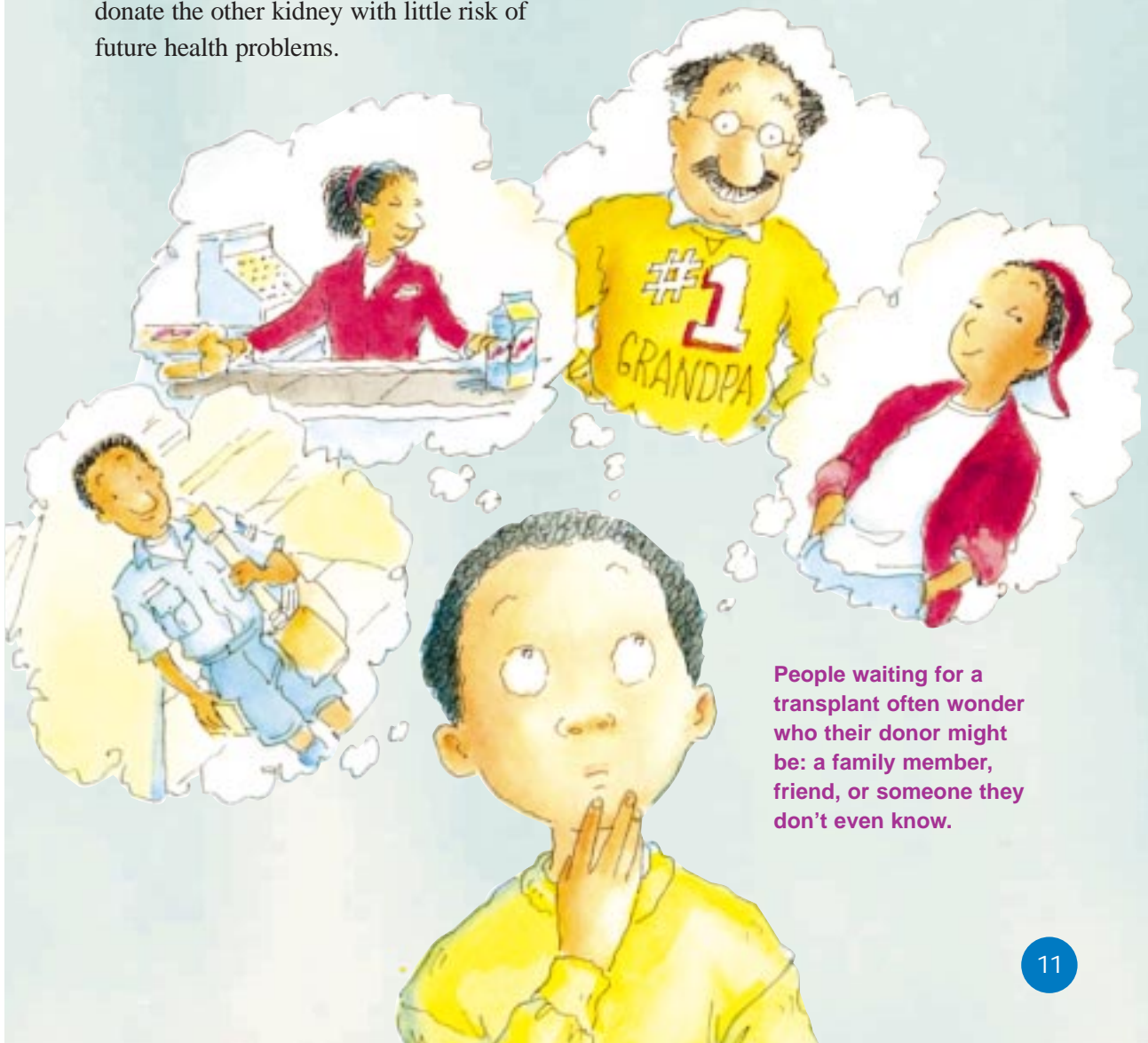
Age 11, 1 year after kidney transplant

How can a living person give up an important organ?

Don't worry—you won't be putting a living donor's health at risk. Here's why.

Kidneys: Nearly everybody is born with two kidneys, but we only need *one* in order to live normally. People can safely donate the other kidney with little risk of future health problems.

Livers: Although people only have one liver, it's a big organ with several sections. Doctors can split the donor's liver into two pieces, giving you a small section which will grow to become full-sized and work normally. The larger section that's left in the donor will grow back to its normal size in just a few months.



People waiting for a transplant often wonder who their donor might be: a family member, friend, or someone they don't even know.

Hospital Questions

Here's some information about your hospital stay—whether you're headed there soon, or on some unknown future date.

Why all the tests?

Before getting a transplant, you'll need to have lots of tests. The results will help your doctor make sure a transplant is right for you at this time.

- A **physical exam** will uncover any other health problems you have, so your transplant team will be better able to care for you while you wait for your transplant. (Unfortunately, some health problems may prevent you from getting a transplant.)
- You'll have **blood tests** to detect any diseases you have and to determine how well your *immune* (infection-fighting) system is working.
- A social worker will **interview** you and your family to make sure you're ready to handle the transplant and the challenging job of caring for your new organ.

Can my family visit me after my surgery?

Young brothers and sisters sometimes aren't allowed to visit after surgery. (This is to prevent the spread of germs to you, and also because you'll be tired and busy learning to care for your organ.) Parents can be with you as much as possible, though, and are usually allowed to stay overnight with you, especially if your hospital is far from home.

How long will I be in the hospital?

After your operation, you'll stay in the hospital until your doctor is sure you're healthy enough to go home (usually around 7 days for a kidney transplant, and about 2 weeks for a liver transplant). Your new organ must be working well, and you have much to learn about caring for it before going home.

What if I don't understand something?

Don't be afraid to ask your transplant team a lot of questions, or to ask the same question more than once. Doctors and nurses will be glad you're interested and want to help you learn more. Write down your questions when you think of them, and jot down the answers when you get them, too.



"My advice is to stay positive and to ask questions—you are the one they're operating on."

Nathan R.

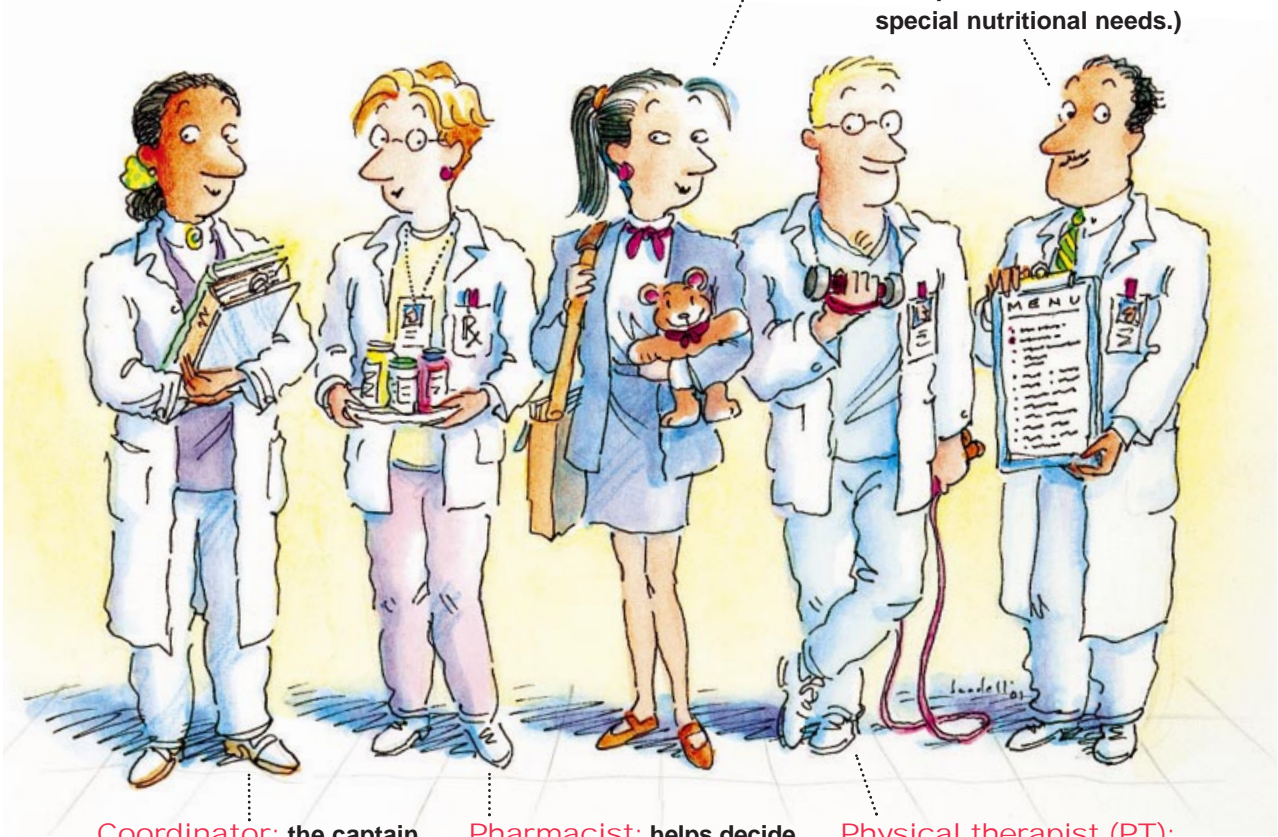
Age 14, 8 years after kidney transplant

Who are all these people?

Your transplant team is made up of lots of people. Each has special knowledge so he or she can care for you. Besides the **doctors** and **nurses** who specialize in transplants, you'll probably also work with the following people:

Social worker: helps you and your family deal with your emotions throughout your transplant experience.

Dietician: suggests meals that will aid your recovery. (Kids getting transplants often have special nutritional needs.)



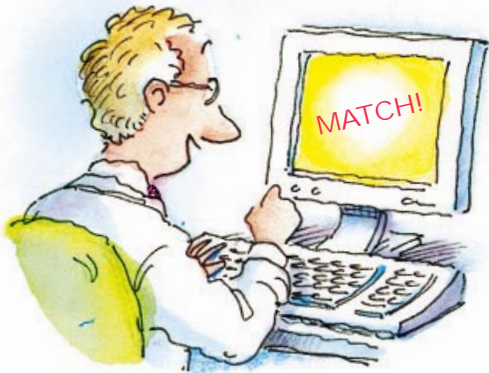
Coordinator: the captain of your team. She or he schedules all the tests for you and your new organ and teaches you everything you need to know about your transplant. If you have questions or problems, go to your coordinator first.

Pharmacist: helps decide which medicines you'll be taking. He or she is an expert on medicines, so if you have any questions—such as when or how to take a pill—or have a problem with the way a medicine makes you feel, talk to your pharmacist.

Physical therapist (PT): recommends exercises for you to do before your surgery (to make you stronger) and afterwards (to help you recover). Follow your PT's advice and you'll feel better much quicker!

The Wait

One of the toughest parts of getting a transplant may be waiting until the right donor is found. These pages explain why you must wait, and what you should do during this time.



Finding a Match

Your transplant team will look for an organ that will match yours as close as possible. This will give you the best chance for a successful transplant. To find a match, you and possible donors will have your blood tested to look for the following things:

- The donor's *blood type* must be "compatible" (able to work with yours). Certain blood types can't mix together.
- **Kidney patients:** It's best if your donor has a similar *tissue type* (special kind of cells that make up your organ). The better the tissue type match, the easier it will be for the new organ to survive in your body.

Living Donor or List?

If a living donor is found for you, the wait for your transplant may be only a week or two. Your surgery can be scheduled as soon as you and your donor have finished being tested. You'll probably be admitted to the hospital the day before your surgery.

If a living donor can't be located, you'll be put on a national computerized waiting list to receive an organ from a seriously injured or ill person who did not survive. (This is called a "cadaveric" donor.) There are lots of people on the lists hoping to receive an organ, so you may have to wait months or even years for your transplant. As soon as an organ becomes available for you, your coordinator will call you, and you'll have to go to the hospital immediately.



“A lot of tests were needed to make sure my dad was a good match. I thought every test was taking forever. When you want something so bad, it feels like forever before you finally get it.”

Ashley N.

Age 13, 4 months after kidney transplant



What to Do While Waiting

The most important thing to do while you wait is to stay as healthy and calm as possible. These tips will help you do that:

- **Get physically fit.** Daily exercise can be fun. Try new activities with family and friends. Ride a stationary bike while listening to music or books on tape. (Check activities with your doctor or PT before you start.)



- **Keep up with treatment.** If you're on dialysis or medications, don't slack off. They're just as important now, and so are your doctor appointments!

- **Visit the dentist.** Cavities or diseased gums could cause serious infections after a transplant, so get a check-up now. Tell your doctor if you have any loose teeth—they should be removed before your surgery.
- **Watch your diet.** Eat nutritious foods that are low in fat and salt. Ask your coordinator or dietician for suggested menus.
- **Get on with life.** Since the wait can be stressful, try to keep busy doing normal things. Don't just sit around waiting! If your worries seem overwhelming, talk with the hospital social worker or psychologist. They're trained to help you during this stressful time. There may even be a support group for kids like you to join.
- **Prepare to go.** You may need to leave for the hospital at a moment's notice, so get whatever you can ready now. Pack loose-fitting clothes, pajamas, a robe, slippers, underwear, bathroom supplies, and things to pass time such as books, a Walkman, CDs, games, and/or small craft kits.

Getting the Call

It may catch you by surprise when you finally get a call telling you a donor organ is available. Here's what you can expect from that moment on.



Ring, Ring!

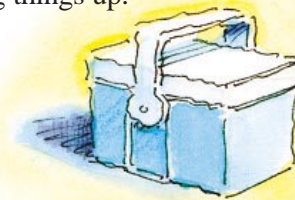
If you're on a waiting list for an organ, it may seem like the call will never come, especially if you've been waiting for months. Then one day your coordinator phones with news that a kidney or liver is available! Kids often say they feel scared, but also excited that the day is finally here.

Before you zoom off to the hospital, there are a few details to cover on the phone. If you have a cold, fever, or are sick in any way, tell your coordinator right away. Your transplant may have to be postponed until you're well again. (A cadaveric organ may be given to another patient on the list.) Your coordinator will also ask when was the last time you ate. Do NOT eat or drink anything from this moment on—your stomach needs to be empty for surgery.

More Waiting?!

You arrive at the hospital expecting to be wheeled into surgery, but the waiting isn't over yet. First you'll need some final tests to make sure no new health problems have come up that would prevent you from having the transplant. It may take several hours to get the test results. And, before your operation can begin, doctors have to remove the donor's organ and examine it. (If you'll be receiving a cadaveric organ, your transplant team may have to travel hours away to another hospital to get the organ.)

To make matters worse, you may also be hungry since you haven't been allowed to eat. If you're feeling very nervous, tell your nurse, and ask your coordinator to keep you posted about any delays. You'll probably feel calmer if you know what's holding things up.



A cadaveric organ will travel to your hospital packed in ice in an ordinary picnic cooler!

A Change of Plans

Even now, your operation can still be cancelled or postponed for the reasons listed below.



- **If an infection is discovered**, it would only get worse after your surgery. The medicine you'll take for your transplant weakens your body's immune system, so it's not able to fight off germs as well.
- **There may be a problem with the organ**, either due to its size (too large or too small), the donor's health history, or even problems that occurred when it was removed.
- **Kidney patients:** You'll get one more blood test called a "crossmatch." A **positive crossmatch** means there are certain cells in your body that will not get along with the donor organ's cells. The donor organ would have a much harder time surviving in your body. (This can happen even if your blood and tissue types match the donor's perfectly.)

If you're sent home, try not to get discouraged. You may have one or more of these "false alarms." For most kids, though, the first organ available is the right one for them! To find out what happens next, read the next chapter.

Time to Go!

These kids explain how it felt to finally head for the hospital.



"When my mom first told me a new liver was ready for me, I didn't want to go.

But it didn't take long for her to convince me that I had to go—I knew I needed it to stay alive and healthy."

Ben Z.

Age 13, 6 years after liver transplant



"We were so excited when the call came that we got ready and left for the

hospital in 1 hour. But after we arrived at the hospital, I waited 12 hours before my surgery finally began!"

Katy M.

Age 14, 3 years after liver transplant



"My doctors found out that I hadn't had chicken pox, so I had to get

vaccinated then wait another 3 months. The 8 months total I had to wait before my transplant felt like 800 years!"

Ashley N.

Age 13, 4 months after kidney transplant



“My dad was my donor. I was worried he was going to be in a lot of pain. After the surgery, I was able to walk before he was, but he got to leave the hospital before me. Now we’re both doing excellent!”

Kate S.

Age 16, 4 years after kidney transplant



“I remember seeing my family next to me when I woke up after surgery, and I had the sensation that everything turned out great and I would be fine.”

Nathan R.

Age 14, 8 years after kidney transplant



“When I woke up from my transplant, everything was like a dream: hazy and very bright. I thought for a few seconds that I was in heaven, but my dad told me I was in the recovery room.”

Steve S.

Age 13, 2 years after kidney transplant



“The most difficult part of my transplant is remembering to take my medicine every day. If I sleep over at a friend’s house, I have to remember to pack my meds, and then I have to remember to take them at the right time. It’s easy to forget because I feel so good now—I don’t feel sick.”

Ben Z.

Age 13, 6 years after liver transplant



“Transplants are a great thing. Be thankful that out of so many kids who need one, you could get one and become healthy!”

Jonathan L.

Age 10, 9 years after liver transplant



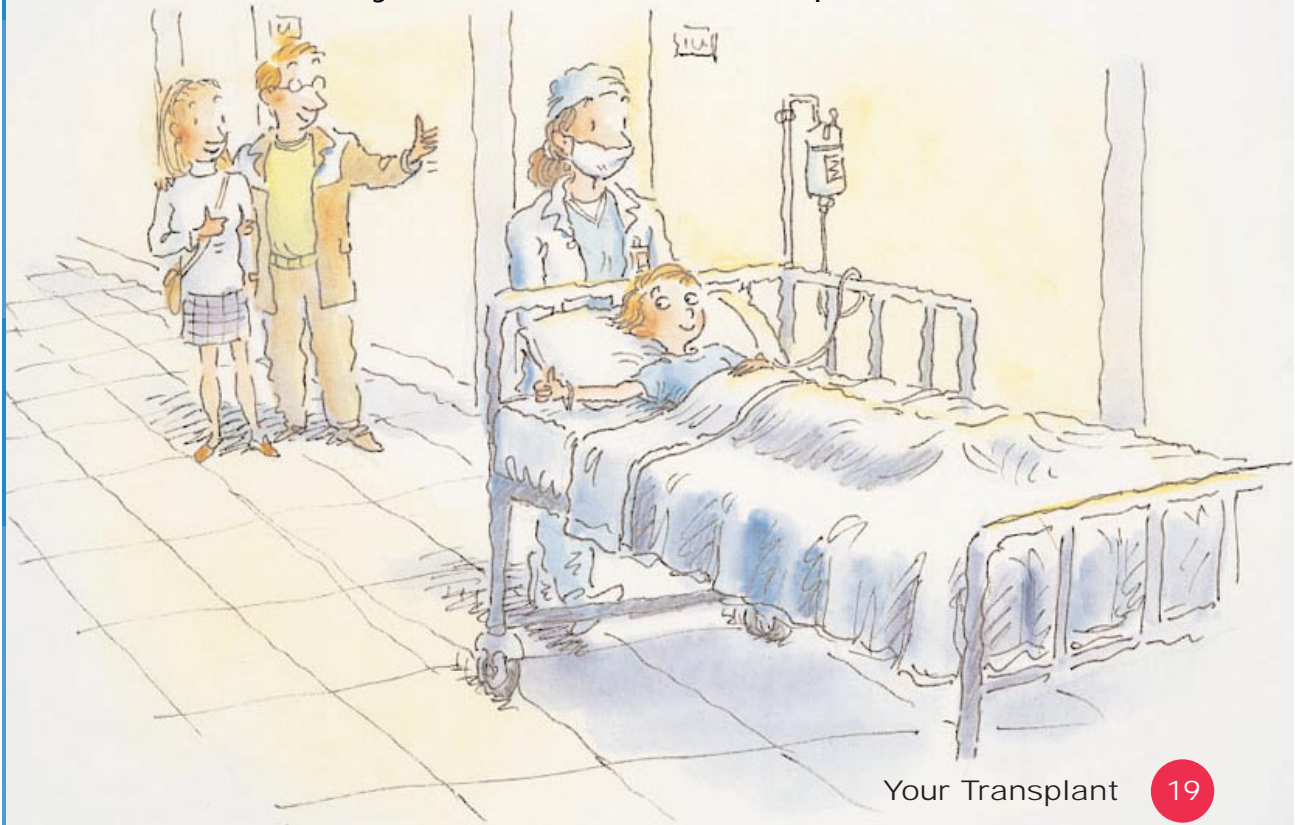
“The medicine I take makes my face puffy, and I’m hairy. When people ask about it, I explain. In my opinion, the side effects are helpful because they let other people know what we have to go through. People recognize that we’ve had to conquer more things in our lives, and they usually admire us for it.”

Jamal B.

Age 13, 8 years after kidney transplant

Your Transplant

It's finally time to get your new organ!
Here's what will happen from the moment
you're wheeled into the operating room
until you walk out the hospital door.



Your Surgery

The waiting is over—it's transplant time! Read these pages before your surgery to find out what happens while you sleep.

Final Preparations

When doctors have decided that both you and the donated organ are ready for transplant, you'll probably be started on powerful medicines that protect the organ once it's in your body. Finally, you're taken into the operating room. There, a team of people will work together for YOU to make sure all goes well. (You've probably already met most of this team, shown below.) Your belly is washed with a special soap that helps prevent infection. By this time, you may already be asleep. Doctors give you medicine, either through an IV or mask, to make you fall into a deep sleep so you won't feel anything during surgery.



"In the operating room, the nurses gave me a hair net to put on my teddy bear's head. I had my surgery with the bear next to me. That made me feel really good."

Erik P.
Age 11, 1 year after kidney transplant

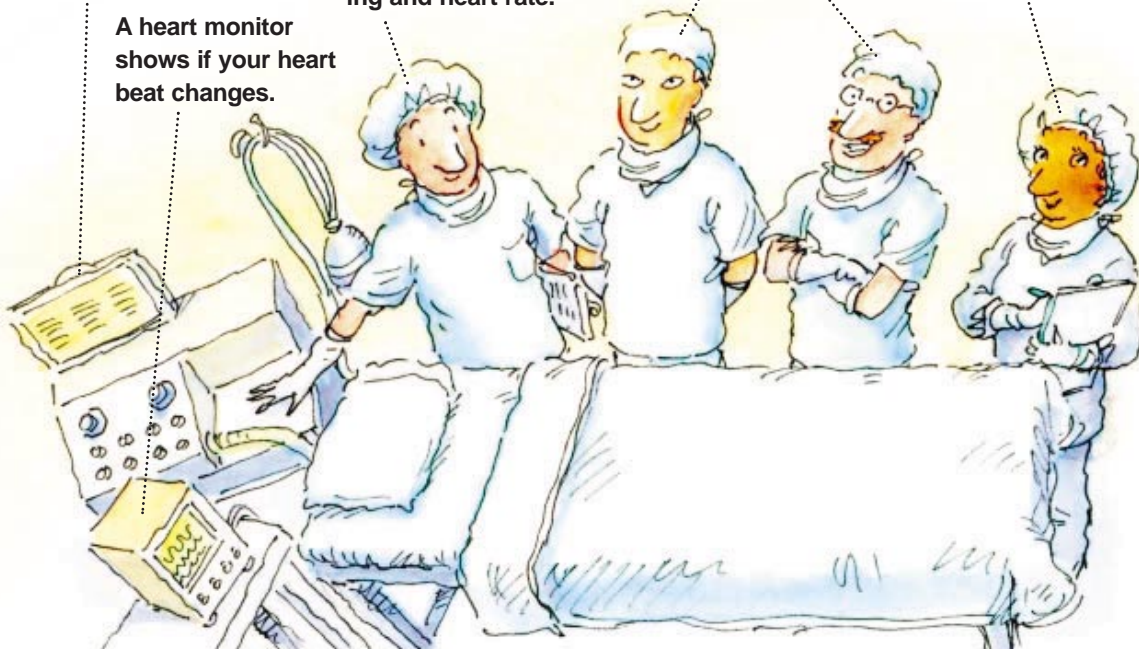
A ventilator helps you breathe during your operation.

The anesthesiologist puts you to sleep and watches your breathing and heart rate.

Two or more surgeons will perform your operation.

Nurses will help the doctors throughout your surgery.

A heart monitor shows if your heart beat changes.

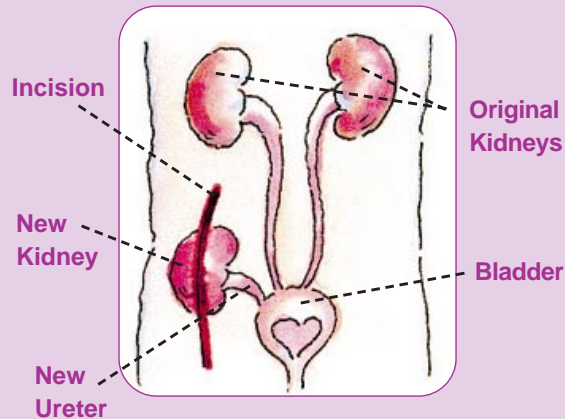


Kidney Transplant

Kidney transplants usually take 2 to 3 hours. Doctors make a cut 4 to 5 inches long in the lower right or left side of your belly. Although your own kidneys are located close to your back, doctors place your new kidney in the front part of your belly because it's easier to get to that area. Your own kidneys are usually not removed unless they're infected. (If they *are* removed, it may be done in a separate operation, either months before or after your transplant. This is to reduce the risk of infection at transplant time.)

Once your new kidney is in place, its blood vessels are connected to your body's blood vessels. The doctor also connects your new kidney's *ureter*—the tube that drains urine from your kidney—

to your *bladder*, the organ that holds urine until you're ready to eliminate it. All connections are checked; then your doctor closes your incision using either special surgical thread or staples. Finally, you're wheeled to the recovery room.

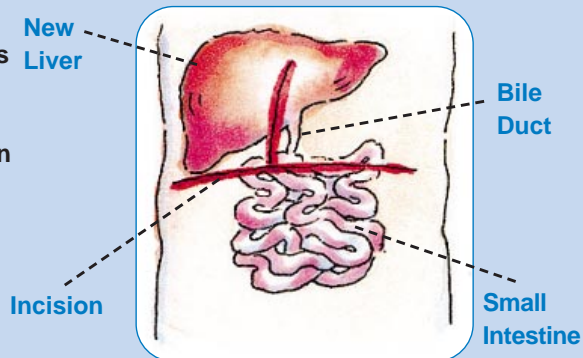


Liver Transplant

Liver transplants can take 8 to 10 hours. (The surgery is longer than a kidney transplant because doctors first have to remove your old liver. There are also more connections to make, and the liver is a delicate organ, so doctors have to work carefully.)

Once you're asleep, a cut is made across your belly, right below your ribs, and another one is made straight up. (The liver is large, so doctors need to make an incision big enough to work in without damaging the organ.) The old liver is removed and the new one is set in its place. Doctors connect the new liver's blood vessels to your body's blood

vessels, and the liver's bile duct to your intestines. The surgeons check the connections to make sure there are no leaks, then close the incision using either special surgical thread or staples. Finally, you're taken to the recovery room.



Your Recovery

Here's a run-down of your recovery, from when you first open your eyes after surgery to the time you're up and exercising.

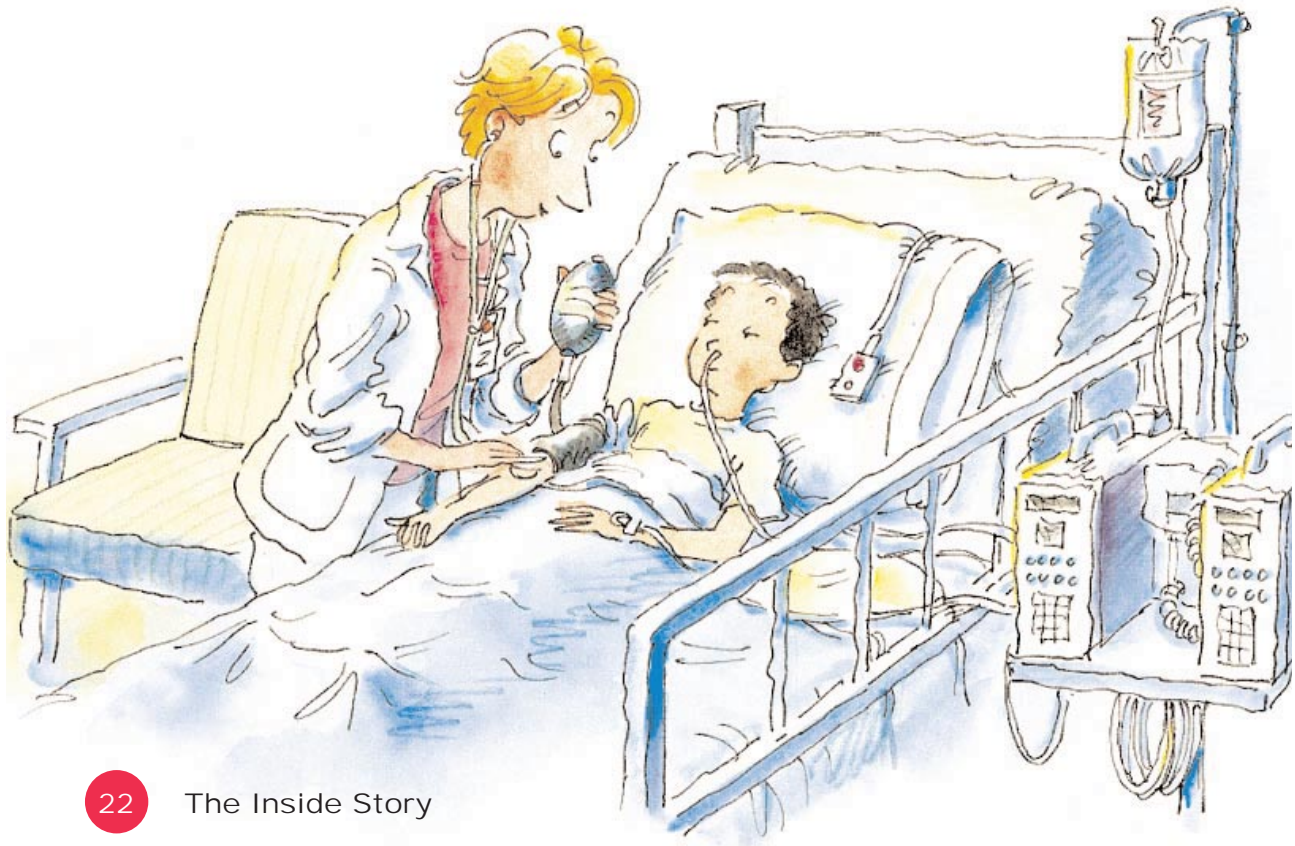


"When I first woke up, I didn't remember much because I was groggy. I remember seeing tubes and weird machines, but I don't remember feeling very much."

Ben Z.
Age 13, 6 years after liver transplant

Waking Up

When you first wake up after surgery, you'll probably feel sleepy and confused due to the medicines used to put you to sleep and to help your pain. Patients usually don't remember much about the first 24 hours after their operation, including any discomfort. Even so, you may have a button to push to give yourself pain medicine. If not, let a nurse know if you're hurting and she or he will give you medicine for relief. Nurses will be in your room often checking your pulse, temperature, and blood pressure.



Tubes, Tubes, Tubes

You'll have lots of tubes coming out of your body to help you recover. (Most will be removed in a day or two; removal can be uncomfortable, but it's over with quickly.) Here's what the tubes do:

- On the first day, you may have a tube in your throat and a "respirator" or "ventilator" machine helping you breathe. (This is more common with liver patients.) You won't be able to talk, but you can communicate by shaking your head yes or no, or by writing.



"The ventilator didn't hurt, but I wanted to talk. My mom had taught me the sign language alphabet before my surgery so I'd be able to ask the doctors and nurses questions. She told them what I was signing."

Alyssa C.

Age 10, 5 months after 2nd liver transplant

- During surgery, an "NG" or "OG" tube was placed in your nose. It removes the air and juices in your stomach so you won't feel sick to your stomach.
- It's normal for fluid to collect in your belly around your new organ. There may be tubes exiting your skin to drain this fluid.
- Instead of eating, you'll get fluids and nutrients through an IV. This will give your stomach time to settle down.



"I was very, very thirsty when I woke up, but I wasn't allowed to drink anything. This made me angry."

Abby P. H.

Age 14, 3 1/2 years after liver transplant

- A tube called a "Foley catheter" was inserted in your bladder during surgery to drain your urine. It may still be in place. Doctors can tell how well your kidney or kidneys are working by looking at the color and amount of urine that's collected in the bag.



It's Healing Time!

While you're in the hospital, it's important to rest so your body can heal. But you'll also need to get out of bed and move around as soon as possible to prevent blood circulation problems. Nurses will encourage you to breathe deeply and to cough to help clear fluid from your lungs and prevent *pneumonia*, a lung infection. Your physical therapist may also show you exercises that will help you get stronger. Follow your transplant team's advice, and you should feel better every day!

Complications

Complications are problems from your transplant that can slow down your recovery and make your stay in the hospital longer.

On the Lookout

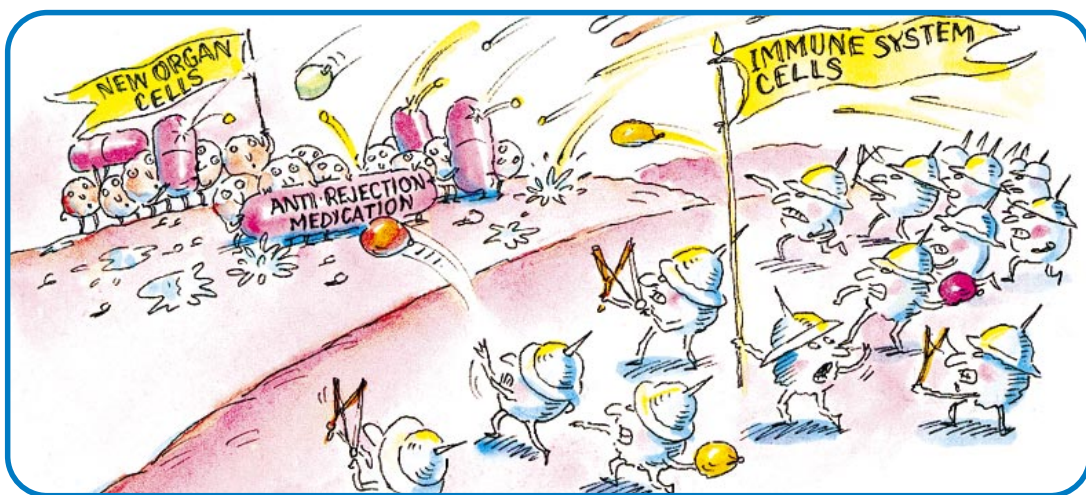
Many patients experience some kind of complication in the first few weeks. Don't panic, though. Your transplant team is constantly watching over you, looking for signs of trouble. They'll treat problems if any occur. Here are the most common ones:

Rejection

Your immune system is like a microscopic army. To protect you, it attacks anything foreign that enters your body, such as germs. Unfortunately, it will also try to destroy or “reject” your new kidney or liver, even if the organ is a good match. This is because the organ's cells are not *exactly* like your body's cells. Rejection can happen at

any time, but it's most common during the first 3 months after surgery. When treated early (with “anti-rejection” medicine), it can be stopped with little or no organ damage.

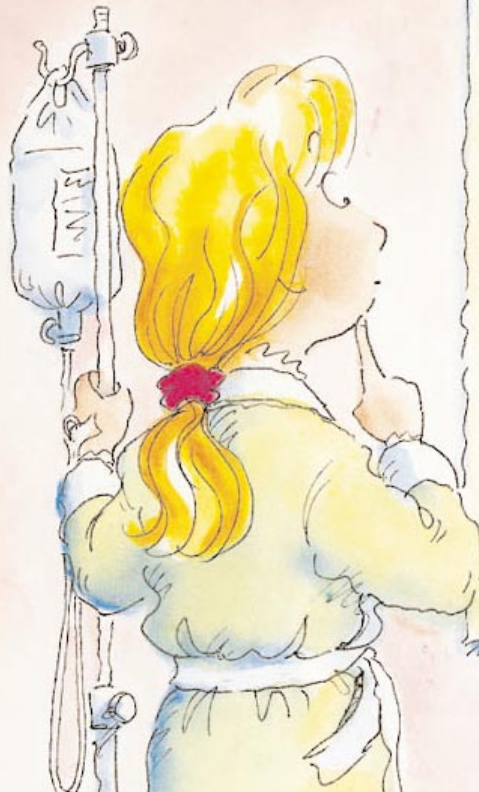
Warning signs of rejection are listed on the poster at the right. Rejection is tricky, though, because it can occur even if you have *no* symptoms at all! Blood tests may tell doctors that your body is rejecting your organ before you notice any signs yourself. Doctors may also perform a *biopsy* to check for rejection: they numb your incision area, then use a needle to remove a tiny sample of cells from your organ. By looking at the cells under a microscope, doctors can see if they are damaged due to rejection. You may get 3 to 4 biopsies in the first 6 months.



Infection

About half of all patients develop some kind of infection. This is because your immune system has been slowed down by the transplant medicines, making it too weak to protect you from germs. And germs are everywhere—in the air you breathe, the food you eat, and everything you touch—so infections are easy to catch. They most often occur during the first 3 months after a kidney transplant or the first 6 months after a liver transplant, when your doses of anti-rejection medicine are highest.

Most infections can be treated with other medicines. Let your transplant team know if you have any of the warning signs shown at the right. (For more about preventing infection, turn to page 37.)



Other Complications

Kidney Patients: It can take time—a few weeks to a month—before your new kidney works normally. You may need dialysis treatments until the kidney can handle the job on its own.

Liver Patients: If your bile duct leaks, bile can drain into your belly. A catheter may be placed into your belly to drain the bile, or the duct may be repaired surgically.

The arteries that supply blood to the liver can sometimes become blocked. If this problem is discovered early enough, doctors can clear the arteries surgically.

Signs of Rejection and Infection

Tell your doctor if you have any of the following signs:

- “flu-like” symptoms (fever, chills, body aches, headache, tiredness, dizziness)
- upset stomach, vomiting, diarrhea
- pain at transplant site
- sudden weight gain or swelling
- breathing difficulties
- cold symptoms (sore throat, coughing up yellow or green mucus)
- a dry cough that lasts more than a week
- a burning feeling when you urinate
- a wound that’s sore or doesn’t heal

Kidney patients only:

- dark yellow or orange urine, or lower amount of urine

Liver patients only:

- jaundice
- light-colored bowel movements

Your Medicines

Now that your new kidney or liver is in place, your most important job is taking the medicines that keep you and your organ healthy.



Anti-rejection Medicines
To keep your immune system from attacking your new organ, you must take powerful anti-rejection medicine (also called “immunosuppressants”). Your doctor will give you the lowest possible dose that will do the job. Since every patient is different, doctors have to try different doses until they discover the best amount for you.

Pills, Pills, Pills



Based on your blood tests, doctors will decide how much medicine you need. Before you leave the hospital, you and your family will learn all about the new medicines you’ll be taking, including how, when, and why to take them. Your medicines will be different than ones you may have taken before your surgery, so your transplant team has lots to teach you. Here are the 3 main types of medicines:

Medicines to Fight Infection

The anti-rejection medicine you’re taking weakens your body’s immune system so it can’t harm your new organ. Unfortunately, this means your body isn’t able to fight off infections as well, either. So you’ll probably have to take one or more medicines called “antibiotics” to keep germs you come in contact with from causing serious infections.

Medicines to Prevent Side Effects

Sometimes medicines cause effects that are not wanted—these reactions are called “side effects.” The powerful medicines you’re taking often cause side effects, especially in the beginning when your doses are very high. Your doctor may give you medicines to treat the side effects that bother you. (To learn more about side effects, see pages 28-30.)

Methods for Medicine

When taking your medicines, there are some very important rules to follow:

- Take your medicines the same time every day, according to your doctor's instructions (with the same food, before or after meals, or on an empty stomach).
- Do **not** drink grapefruit juice or eat grapefruit—they can increase the amount of medicine in your blood and cause side effects.
- Never skip or change a dose of medicine on your own, even if you're feeling better.
- If you forget to take—or vomit—a dose, call your transplant team to find out what you should do.



- Never take any other medicines (even aspirin, or cough, cold, or herbal medicines) without first checking with your transplant team.
- For tips to help you keep track of all your medicines and never forget a dose, turn to page 37.

Pill-Taking Tips

Find pills hard to swallow?
Follow these kids' advice.



"I take 22 pills a day. Drinking water from a *bottle* helps me swallow them.

The water goes right to the pills and carries them down my throat—they don't float around in my mouth like if I drink from a cup."

Dylan S.

Age 8, 8 months after 3rd liver transplant



"If you have trouble taking pills, ask your doctor for the liquid forms of the medicine. Swallowing pills with applesauce helps, too."

David A.

Age 9, 1 year after kidney transplant



"I had never taken pills before, only liquid medicines. My nurse told me I could practice taking my pills by swallowing a Tic Tac with water or juice."

Tiffanie C.

Age 11, 4 months after kidney transplant

Side Effects

The medicines you're taking can cause unpleasant side effects. Here's a head-to-toe list of the most common ones.

Doc Talk

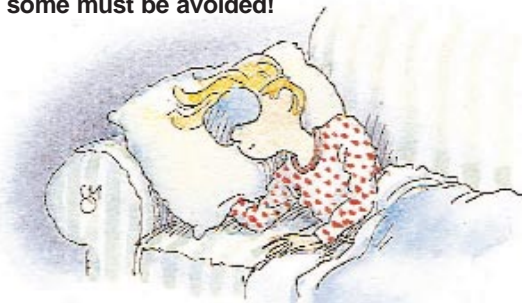
You may experience a few, many, or none of the side effects listed on these 3 pages. Fortunately, side effects usually decrease as your doses of medicine are lowered. (Your doctors will most likely lower your doses as your body gets used to the new organ.) It's important to know what side effects are normal, though, so you can report any unusual reactions to your doctor.

Even if you're experiencing normal side effects, tell your doctor—he or she may be able to adjust or change your medicines to relieve some of your symptoms.

Headaches

Emotional and physical stress can cause headaches. So can high blood pressure, which is a side effect of some medicines you may be taking. (See page 44 for an explanation of high blood pressure.)

What you can do: Rest or nap in a dark room. Avoid the things that trigger your headaches, such as certain activities or foods. Ask your doctor which pain medicines you can take—some must be avoided!



Mild Hair Loss

Hair strands may get weak, dry, and break off at the roots, making hair thinner overall.

What you can do: Use a conditioner after shampooing, and don't dye, perm, or bleach your hair.



Unwanted Hair Growth

Fine, dark hair may grow on your upper lip, back of neck, sides of face, arms, or back.

What you can do: Talk with your parents, doctor, and coordinator about ways to make the hair less noticeable. You may be able to bleach, trim, or shave it, or have it removed.

Swelling

Fluid may build up in face, hands, and legs.

What you can do: Cut down on salt, drink more fluids, sit with your feet raised, and avoid tight-fitting clothes, shoes, and jewelry. Your doctor may prescribe water pills, which help you eliminate extra water through urine.

Brain Changes

Your medicines can affect the way you think, feel, and act. You may feel angry, nervous, impatient, depressed, or guilty. Other normal reactions are mood swings, panicky feelings, hallucinations (imagining something that's not there), and trouble concentrating, sleeping, or remembering things.

What you can do: The most severe reactions—if they happen at all—usually only occur in the first few weeks, when doses of medicines are strongest. Transplant stress can cause some of these problems, too, so talk with the social worker or psychologist about how to reduce this stress.



“At first, I had bad mood swings. I'd get real happy, then real sad or mad quickly. We asked my doctor if I could take the medicine that caused this at night instead of in the morning. Now I feel 100 times better!”

David A.

Age 9, 1 year after kidney transplant

Diabetes

Diabetes is a higher than normal amount of sugar in the blood. It can cause you to feel very thirsty, have to urinate more often, have blurred vision, or feel confused. It can also lead to serious kidney problems.

What you can do: Doctors will prescribe medicine to lower your blood sugar (either pills or daily injections of *insulin*—the natural chemical that moves sugar out of your blood and into your cells). You should also exercise, watch your diet, and maybe lose weight.



Overgrown Gums

Your gums may get puffy and start to grow over your teeth. It's not uncomfortable, but you may not like the way it looks and can have a harder time cleaning your teeth.

What you can do: Brush 3 to 4 times a day with a soft toothbrush. Floss, massage gums with your finger, and use medicated rinses to prevent infection. Visit your dentist regularly.



“I've had two gum surgeries. It was hard for me to eat when my gums were overgrown. They were sore for a few days after surgery, but once they were smaller again, I could eat better.”

Clifford M.

Age 13, 6 years after kidney transplant

Acne

Your skin may become oilier, causing your face, chest, shoulders, or back to break out.

What you can do: Gently wash your skin 3 times a day with mild soap. Avoid rubbing, and don't pick blemishes or use cosmetics. See a skin doctor if skin becomes infected.

Tremors or Numbness

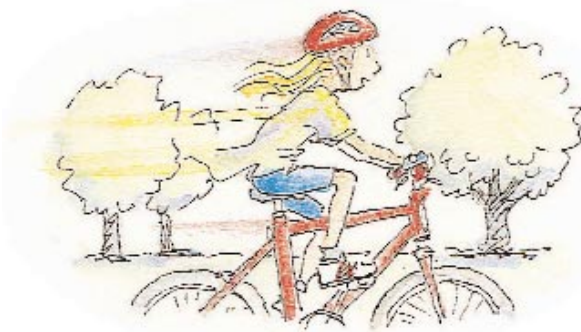
Hands and feet may shake slightly or tingle.

What you can do: Trembling is usually mild and doesn't require treatment. Still, let your doctor know, since it may be a sign that your drug levels are too high. Also, ask your physical therapist for some stretching exercises, which may give you temporary relief.

Weight Gain

You may feel hungry all the time. Watch out! If you eat the wrong foods, you could gain too much weight. Fat may settle around your belly and upper back or neck, making you look slightly hunched.

What you can do: Avoid high-calorie foods, especially those high in fat (like fries, chips, and other snack foods). Daily exercise is the best way to keep your weight down. (For more on diet and exercise, see pages 38-39.)



Stomach Problems

Medicines may cause stomach upset, cramps, vomiting, heartburn, or diarrhea.

What you can do: It may help to take medicines with water or food, after meals, or at bedtime. Check with your transplant team to find out which methods you can try. Your doctor may also prescribe medicine to calm your stomach.



Bruising Easily

Bruises form when you bump a body part and blood leaks out of a blood vessel under your skin. Some medicines thin your skin, so blood vessels break more easily. Other medicines lower your *platelet* count (platelets are the cells that help clot your blood), so blood leaks stop more slowly.

What you can do: Show your doctor bruises in unusual areas (chest, inner thighs, or arms). He or she may adjust your medicine to allow the platelet count to return to normal.



"In the beginning, my gums swelled up, I got hairy, and I was a chunky monkey. But once my doses were changed or lowered, the side effects went away. I actually think I look better now than I did before my transplant."

Steve S.

Age 13, 2 years after kidney transplant

Do You Mind?

With all the discomfort a transplant brings, you may wonder: will I ever feel normal again? In the next few months, you should begin to have more energy and feel better than you did before your surgery.

But what if your medicines have changed your appearance, causing weight gain, acne, or other problems? You may feel self-conscious or upset. This is normal—you're not used to seeing yourself this way. Instead of focusing on your appearance, though, try to concentrate on healing and getting back to the activities you enjoy. Remember, the changes are only temporary. And having a healthy outlook will help you feel better faster. So take charge of your attitude and focus on the good things a transplant brings—like feeling more energetic or not having to be on dialysis.

Keep in Mind

Most important, don't let side effects tempt you to skip a dose or stop taking your medicine—you could wind up back in the hospital, or even lose your new organ! Tests will show if you skip, and your body would know, too—eventually it would start feeling sick again. Your new organ is valuable, so take good care of it!

Also, keep in mind that coordinators, pharmacists, and doctors are always there to help, so call them to discuss any problems you're having with side effects. They may have tips for how to deal with some.



“Think of your transplant as an adventure. It’s a part of your life that you *have* to go through, so live with the adventure as best you can.”

Ben Z.

Age 13, 6 years after liver transplant



Fun Things to Do

Looking for ways to pass the time while you're in the hospital or stuck at home healing? Here's a list of things to do that will make time fly!

1 Learn a new joke every day and pass it on to your doctors, nurses, visitors, and other patients. Ask others what their favorite jokes are, and spread those around, too. (Joke books and computer web sites are good places to find laughs.)



2 Make a tape recording or video for your class at school, your best friend, or siblings at home explaining what happens on your unit in a typical day. It'll help them understand what you're going through.

3 Sketch things or people in your room.



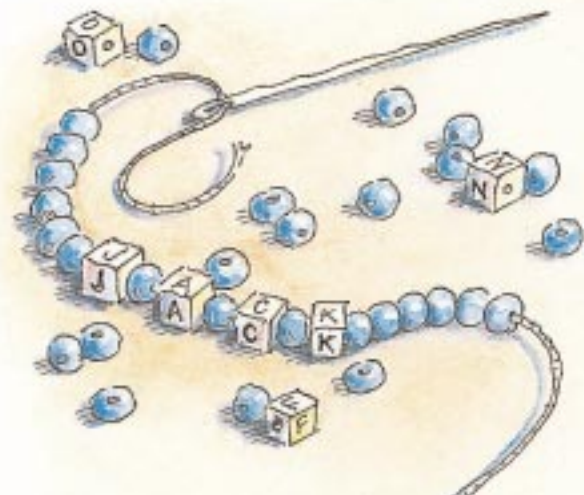
4 If your buddies can't visit you, suggest that they get together at one friend's house and take turns talking on the telephone with you.

5 Write a fan letter to someone you admire: your favorite singer, author, actor, athlete, or member of your transplant team.



6 Start a diary or journal or add to one you already have. Here's a short writing idea: using only 4 words, describe your room, a person you just met, or your mood each day.

7 Ask a parent to bring you string and beads from a local craft store to make friendship bracelets. Then hand out your handiwork to other kids on the unit.



8 Make a cheer-up chart. Write down at least one good thing that happens to you each each day. Some days it may be as silly as “At least an elephant didn’t sit on me today!”

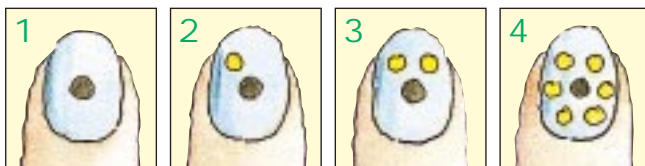
9 Imagine a sporting event, dream vacation, or concert you’d like to go to or be a part of. Draw your ideas, write them down, or simply escape to these places in your mind whenever you want.



10 If you have computer access to the Internet, email your classroom a new question each day. Here’s one to start with: if you could take a trip anywhere in the world, where would you go, and why?

11 Ask the members of your transplant team and other friends you’ve met in the transplant unit to sign the inside back cover of this book. Keep it as a reminder of this experience you’ve shared together.

12 Paint your fingernails and toenails in cheerful colors. For fancy, fun flowers, follow the steps below.



Beating Boredom

Here’s how these kids kept busy in the hospital.



“I painted model cars, planes, and boats. Then at Christmas, I gave some away to people in my family for presents.”

Joe R.

Age 10, 1 year after liver transplant



“I went on rounds with the liver team. I want to be a pharmacist, so visiting other transplant patients with all the doctors helped me see that it would be a great job.”

Alyssa C.

Age 10, 5 months after 2nd liver transplant



“I was back in the hospital on my birthday because I had rejection. It was cool, though, because I had my party there, with my family, a cake and presents.”

Tiffanie C.

Age 11, 4 months after kidney transplant



“When I was going home, I was afraid I was going to mess up with my medicines. I was also nervous about seeing my friends—it had been a few months since I’d seen them, and I had changed physically because of my medicines. They’ve been completely supportive about everything, though.”

Kate S.

Age 16, 4 years after kidney transplant



“A liver became available 2 weeks before my sister’s wedding. I didn’t want to miss the wedding, but I couldn’t pass up a new liver! I had my surgery, and actually got to go to the wedding for a few hours. I was tired, but happy.”

Katy M.

Age 14, 3 years after liver transplant



“Before my transplant, I just sat during recess because I was too uncomfortable to move a lot. Now I’m playing and running around with the rest of the kids for the first time.”

Robert B.

Robert B., Age 5, 1 year after liver transplant



“My older brother, Ben, had a transplant, too. Our friends know that we can’t play tackle football, so they switch to another game when we come play. It’s helped me to have my brother go through the same thing as me.”

Michael Z.

Age 8, 4 years after 2nd liver transplant



“Before my transplant, I couldn’t wear normal clothes because my belly was so big. I wore mostly jogging pants and big t-shirts. But 3 months after surgery, I wore normal clothes for the first time, and I had lots of energy.”

John B.

Age 10, 4 years after liver transplant



“I feel totally comfortable talking to my friends about my transplant because it was a great thing. Since I’ve shared what I know about transplants, some of my friends might become organ donors one day if they have the chance.”

Nathan R.

Age 14, 8 years after kidney transplant

After Your Transplant

How will life change with your new organ? Will people treat you differently? Will you be able to do things you couldn't do before? This section tells what to expect once you leave the hospital.



Home at Last!

As soon as your doctor thinks you and your organ are ready, you'll be on your way home. Here's what you'll need to know during the first 3 months, when complications are most likely.



Leaving the Hospital

Once home, *you'll* be in charge of your health. At first, you may need to write down things daily like your temperature, weight, blood pressure, or fluid intake so your transplant team can keep track of how you're doing. (Before you leave the hospital, they'll teach you and your family how to do all this.) You're probably excited to return to family and friends, but you may also be afraid you'll forget everything you learned about caring for your organ. Don't worry—you'll be able to reach someone 24 hours a day. Call your coordinator whenever you have any questions or concerns.

Clinic Visits

In the beginning, you'll need to return to the hospital's outpatient clinic one or more times a week. This is so your transplant team can check how well your organ is healing, adjust your medicines, and detect any complications you may be having. You'll be examined and have your blood tested. Bring your list of medicines and dosage amounts to your appointments. (If you don't live close to your transplant center, you may stay in a nearby hotel or Ronald McDonald House for a few weeks so you can return to the clinic easily.)

After the first month, you'll visit the clinic less often. But your appointments are still very important. Remember: even if you feel fine, you can still have a rejection! If tests show you have a problem that needs special care, you may be readmitted to the hospital.

Infection Prevention

Here's a list of things you can do to reduce your risk of getting an infection during your first few months back home.

- ✓ Avoid anyone who is sick. Ask all visitors to wash their hands.
- ✓ Avoid crowded indoor places (such as malls, movie theaters, gymnasiums, etc.) particularly during the winter cold and flu season.
- ✓ Wash your hands often with antibacterial soap (especially before eating and after going to the bathroom or handling pets).
- ✓ Don't drink out of anyone else's glass, or share eating utensils or towels with others.
- ✓ If you have a pet, don't clean its litter box or cage. Don't let pets lick your hands or face, and keep them out of your bedroom.
- ✓ Avoid touching your eyes or nose—the main paths for germs into your system.

Sometimes infection is unavoidable. If you notice any of the signs of infection listed on page 25 call your doctor or coordinator.

More Medicine Advice

It may take a while to get into the groove of taking your medicines at home. You'll need to swallow some once a day and others more often, some before meals, some after. Things will get easier after a while. The amount of medicine you'll take will decrease, and you may even be able to get off some completely. Here are a few tips to make taking your medicines easier:

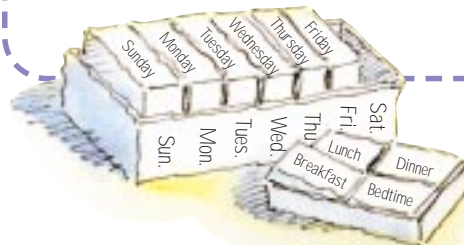
- Your hospital or pharmacy probably gave you a list of your medicines and the times to take them. To help you remember, hang this list where you'll see it during the day. If you weren't given one, you can make your own.
- Set a timer on your watch or alarm clock to remind you when it's time for a dose.
- Ask your coordinator or pharmacist for helpful hints. For example, you may be able to schedule doses around daily routines such as brushing your teeth.



"I organize my pills in a case marked with the days. On the door of the cabinet where I keep my case, we put an 'M' (for morning) and an 'N' (for night). When I take my morning dose, I move a thumbtack over from the 'M' to the 'N.' I can see at any time if I took my pills."

Sean B.

Age 11, 3 1/2 years after liver transplant



Eating and Exercise

A nutritious diet and regular activity will speed your recovery and help keep you healthy. So jump right in and eat right up.

A Weighty Issue

Kids who've had a transplant need to eat well so their body gets the nutrients that will keep it strong. A healthy diet also helps keep your weight under control. Unfortunately, it can be easy to put on the pounds after surgery. Some medicines make you hungry all the time. And if your diet was limited before your transplant, you may be eager to eat your favorite foods again.

Your doctor or dietitian may suggest an eating plan for you to follow. Weighing yourself daily will also help you stay on track. If you think you need to lose (or gain) weight, ask your doctor or dietitian for advice.



Diet Dos and Don'ts

Unwanted weight gain isn't the only reason to watch your diet. By steering clear of certain foods, you can avoid other health problems, like high blood pressure and high cholesterol (both explained on page 44) and illness caused by bacteria on food. So keep these points in mind when it's eating time:

- **Do** stick to foods low in fat, sugar, and salt. (Too much salt can lead to high blood pressure.)
- **Do** eat a variety of vegetables, breads, cereals, lean meats, fish, poultry, fruits, and low-fat, pasteurized dairy products (unless your doctor has restricted any of these).
- **Do** peel or cook fresh fruit and vegetables grown in soil (such as carrots) before eating them. This will remove any bacteria.
- **Do** drink lots of fluids such as water, herbal teas, fruit juices, and pasteurized low-fat milk.
- **Don't** eat canned foods, which are often full of salt.
- **Don't** eat sweets or salty snacks between meals. (Ask your dietitian for a list of recommended snacks.)
- **Don't** drink "sports drinks" without first checking with your doctor. Some contain large amounts of sugar, sodium (salt), and potassium (which is hard on the kidneys).
- **Don't** eat anything that includes raw eggs such as raw cookie dough. (Cooking the eggs will kill any bacteria they may have.)

Active Ideas

Daily activity is good for many reasons. It helps strengthen muscles that may have become weak while you were sick. Exercise also gives you energy, boosts your mood, reduces stress, improves sleep, and helps control your weight.

Follow your transplant team's advice for exercising. Start out slowly—maybe a daily walk. As you become more active, be careful not to overdo. Rest whenever you're tired, and stop if you feel pain, shortness of breath, dizziness, or a pounding heart beat. Avoid contact sports where bumping into others while playing is common—this could damage your new organ. Within a few months, you'll probably be back to your old self—or better! Many kids feel good enough to try new activities they've never done before.



Food for Thought

These kids watch what they eat and get up on their feet!



"My medicine made me gain weight, so I ride my bike and walk a lot. We also

buy fat-free, low-salt food. The fat-free fudgesicles taste so good I could eat them every day!"

David A.

Age 9, 1 year after kidney transplant



"I was concerned I wouldn't be strong when I got back into basketball, so

I ran and practiced on my own. It helped me recover and teammates said I really improved!"

Leanna J.

Age 16, 1 1/2 years after kidney transplant



"I only have candy once in a while. Dark chocolate stops the cravings

better than milk chocolate. I put it in the freezer and just take a small piece now and then. That way I don't eat too much—I have to suck on it."

Ashley N.

Age 13, 4 months after kidney transplant

Family Matters

It can take a while for everyone in your house to adjust to living with your transplant. Here are some tips to handle hassles at home.



Your Stress

All patients and their families have a bad day once in a while. If at times you feel like you can't control your emotions, remember: this can be due to your medicines or to stress that you're dealing with right now. (Stress often shows up when people go through big life changes. It can make you feel angry, worried, sad, and/or restless.)

To relieve stress, do an activity you enjoy or one that helps you relax. Listen to music, go on a bike ride, or do a crafty hobby—anything that helps you focus on something positive. Some kids write their thoughts in a journal. Once their feelings are down on paper, they can close their book and leave their stress behind.

Parent Problems

Kids sometimes feel that their parents are overprotective or don't trust them to take their medicines on their own. Your transplant team may have encouraged you to take responsibility for your medicines, but they'll probably want your parents to check up on you, especially in the beginning, since forgetting a dose can be dangerous.

If you take your medicine every day on your own *without* being reminded, your parents will probably worry less. They may even give you more freedom to do other things on your own because they'll trust you'll make the right decisions for your health. If you *do* miss a dose, though, be sure to tell your parents and call your doctor to find out what to do. Don't hide your mistake—your medicine is too important!



"My mom knows I'm forgetful sometimes. Whenever I go on a sleepover, I call home to tell her that I've taken my medicines. Then she doesn't worry."

Ashley N.

Age 13, 4 months after kidney transplant



Sibling Struggles

There may be times when you feel angry at your brothers or sisters because they're healthy and you've had to go through so much. You have a right to feel upset—transplants aren't easy! Just keep in mind that your illness has probably been hard on your siblings, too. Brothers and sisters may feel angry or alone if a parent spent lots of time with you in the hospital, away from them. They may feel jealous of all the

attention you're getting. They may even feel guilty that they've been well while you've been sick. Your siblings have a right to their feelings, too.

If you've been arguing with them lately, try holding a family meeting. Let all family members share how they feel. Understanding what everyone is going through is the first step toward getting along.

Back to SCHOOL

If you've been out of school for a while, going back can be a big deal. Here are some tips to make it a smooth move.

Teacher Talk

Your doctor will let you know when you can return to school. You may start out going a few hours a day and work your way up to full time. Your parents should let your teachers know that you may need to rest or take medicine during the day, or use the bathroom more often.

If a certain side effect makes school-work more difficult, your teacher may have a solution. For example, if you have hand tremors that make it hard to write, perhaps you can type your classwork and tests on a classroom computer.

Classmate Communication

It's exciting to return to school, but you may also worry that classmates will treat you differently. Most kids say their friends gave them a warm welcome back. If your appearance has changed due to medicines (if your face is rounder or you have excess hair), you may feel anxious about what classmates will think. Kids often say it helps to talk about their transplant and answer questions classmates may have. Friends will soon see that you're still the same person—just healthier now!



"My friends are great listeners. I can always call them for comfort. That's why my mom says 'Friends are the best medicine!'"

Ashley N.

Age 13, 4 months after kidney transplant



bendell

Support for You

If you don't feel comfortable talking about your transplant with classmates, that's OK, too. Some kids say it's easier for them to talk with people in a support group—others who have gone through the same thing. Ask your coordinator or social worker if your hospital or community has one you could join.



"I go to a support group at my hospital. Even though it's mostly adults, it's fun. Most people haven't had transplants—they're waiting—and we tell them what it feels like."

Alyssa C.

Age 11, 5 months after 2nd liver transplant



Your coordinator may even be able to help you find a chat group for transplant patients on the Internet so you and your family can ask questions and get support. Talking with a counselor—on your own or with your family—can also help you adjust to life at home and back at school.

School Solutions

These kids tell how they handled challenges in class.



"I was away from home over 4 months. Going back to school and seeing all my friends helped me feel normal again. I showed my class pictures of me in the hospital. It helped them understand."

Sean B.

Age 11, 3 1/2 years after liver transplant



"I taught my class how to wash their hands to help me stay healthy. I told them to say the ABCs while soaping up so they know how long to wash."

Joe R.

Age 10, 1 year after liver transplant



"I'm supposed to drink lots of water but avoid water fountains because you can get germs from them. So my teacher let me keep a water bottle at my desk. She let the whole class have bottles, too, to be fair. They thought it was great!"

David A.

Age 9, 1 year after kidney transplant

Long-Term Problems

High Blood Pressure:

Some medicines cause blood to push too hard against the walls of your blood vessels. This is called “high blood pressure.” You probably won’t feel any symptoms, but this can weaken your blood vessels and lead to heart or kidney damage. Your doctor may give you medicine to lower your blood pressure. It’s also important to exercise regularly and avoid salty foods.

High Cholesterol:

High cholesterol occurs when fat collects in your body’s blood and tissues. This can lead to heart problems. Transplant medicines can cause high cholesterol. Doctors may give you other medicines to lower your cholesterol. It also helps to eat a low-fat diet and exercise regularly.



Sensitive Skin:

Your medicines can make your skin more sensitive. You may sunburn easily, so always protect your skin when you go outside, even on cloudy or winter days. Wear a hat, long sleeves, and pants when possible. Use sunscreen with SPF (sun protection factor) of 15 or higher, especially on your face, neck, and hands.



Cancer Risk:

Transplant medicines may increase your chances of developing some kinds of cancer. This is because your immune system is slowed down and can’t destroy cells in your body that didn’t form properly. The abnormal cells can spread, becoming cancerous. Regular checkups give your doctor a chance to treat any problems before they become serious. Protecting yourself from the sun will help you avoid skin cancer.

Because your risk of rejection never goes away, you'll probably take some medicine the rest of your life. Here are some effects of taking medicine for a long time and ways to prevent problems.

Kidney Problems:

Blood tests will show if the medicines you take bother your kidney or kidneys. If so, your doses will probably be lowered. Tell your doctor if you feel tired all the time or use the bathroom often during the night—other signs of kidney problems.

Slowed Growth:

Medicines may also keep kids from growing as fast as they normally would. Your doctor may be able to reduce or change your dose. This may help you catch up.

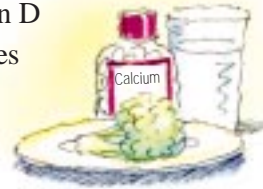
Risk of Infection:

Anti-rejection medicines reduce your body's ability to heal cuts and fight off germs. Your risk of infection may continue to be greater than normal. Keep your skin clean. Regular dental checkups and teeth cleanings are also important.



Osteoporosis (Bone Problems):

Medicines can cause bones to become brittle and break easily. Your doctor may prescribe calcium pills. Foods high in calcium and vitamin D will also make bones stronger. (Ask your dietician for a list.)



Rejection:

Although it doesn't happen often, your body can still reject your organ even years after your transplant. At clinic visits, doctors will continue to test your blood for signs of rejection and increase your doses if necessary. Call your transplant team if you have any of the signs listed on page 25. (Note: unlike the other problems listed on this page, rejection results from *too little* medicine, not *too much*.)

It's Worth It!

Your new organ will make your life better in many ways. Still, you'll always have to keep a close eye on your health. Lab tests and checkups can catch problems while they're still small. These tests may seem like a drag, but remember: you'll need your organ for a long time. It's worth the extra trouble to take care of it!

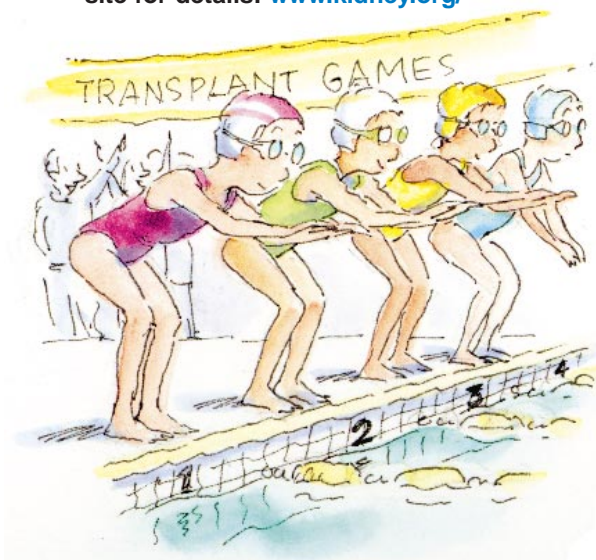
Focus on the Future

Now that your transplant is behind you, it's time to get back to living! The experiences you've had may even make life better.

Living a Full Life

If you were sick for a long time before your transplant, it may seem odd that you can now exercise, go to school, or do other things kids normally do. Then again, if you were active right up to your surgery, you're probably eager to get back to doing all the things you used to do. Here are some transplant activities you might like to try.

- **Enter the Transplant Games:** The U.S. Transplant Games are a 4-day, Olympic-like competition held every other year. Anyone who has had a transplant can enter. You can compete in 13 different sports, including basketball, track, tennis, swimming, cycling, volleyball, and bowling. Kids of all ages and from all over the country participate. It's organized by the National Kidney Foundation. Call or check their web site for details: www.kidney.org/



- **Celebrate Your Success:** Each year many kids celebrate the special day they got their transplant. You may want to mark the occasion by throwing your own yearly party. If your donor was a living relative or friend, invite that person as your honored guest.



- **Contact Your Donor's Family:** If you received a cadaveric organ, you may want to write the donor's family a letter. (Their name and address are kept private, but your coordinator can send the letter for you.) What should you write? You might explain how badly you needed the organ and how much better you're doing since your surgery. You can also thank the family for their wonderful gift. Sign your first name only, and don't seal the envelope—your coordinator will do that. Even if you don't hear back from the family, the letter can make you both feel

good.

How You've Changed

Kids who've had a transplant often think they look at life differently now. Many feel they make the most of each day and don't waste time being unhappy about unimportant things. Others say their transplant made them stronger and better able to handle tough situations. They've already met a huge challenge, so when a new problem arises, they feel confident they can overcome it.

Now that you've accomplished so much, you may feel like trying activities you never did before.

Go for it! Learn to play an instrument, take karate lessons, try out for a school play. Learning new skills is fun, and it's a great way to thank your donor for the amazing gift.



How You Can Help Others

Would you like to help other kids the way the kids in this book helped you? Here are some ideas. You could organize a toy collection or fundraiser for the kids at your transplant center. Or you could write cards or make decorations to send to transplant patients at holiday time. And finally, write to the address below or visit <http://www.fujisawa.com> and tell us about your transplant experience. We'll post as many comments as we can on this site so that other kids can learn from you. Let us hear from you!

Fujisawa Healthcare, Inc.
Medical Information Dept.
Three Parkway North

Life Is Great!

Transplants have inspired these kids to do great things!



"I've spoken at fundraisers for kids who are waiting for a transplant. My mom and I also meet with families to show the kids they can get through this and become as healthy and normal as me."

Lindsey D.
Age 12, 11 years after
liver transplant



"Since we'll never know who gave me my liver, every year on the date of my transplant we give a gift without telling who we are. Last year we set up a fund at my hospital for people who need emergency transplants."

Joe R.
Age 10, 1 year after
liver transplant

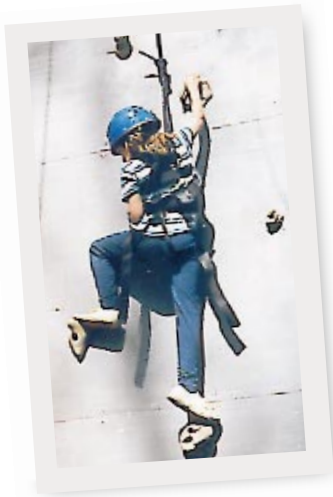


"I'm writing a book about my transplant to help other kids. They'll be able to write their own feelings and experiences in it. I also want to do a newsletter—with other kids' stories and pictures—to hand out at hospitals."

Ashley N.
Age 13, 4 months after
kidney transplant

Transplant Power!

Thanks to their transplants, these kids have the energy to do the things they love again—and try *new* adventures, too!



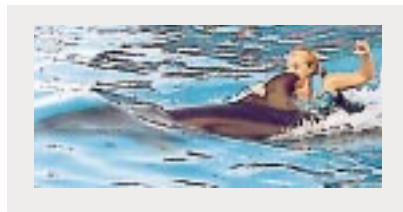
Lindsey D. conquers a climbing wall at a transplant camp for kids.



Erik P. (left) has a black belt in Tae Kwon Do. He does moves like this takedown, but no contact fighting.



John B. got back on his horse, Frosty, as soon as he could after surgery.



Kate S. swam with dolphins after healing from her transplant.



Jamal B. (left) won the gold in the 50-yard dash his first time at the U.S. Transplant Games.



Doug B. snowboards down hills in his backyard.



Katy M. says sports help keep her strong and healthy.

AUTOGRAPHS

*My friends and team members have signed their names here.
I'll remember their kindness year after year.*