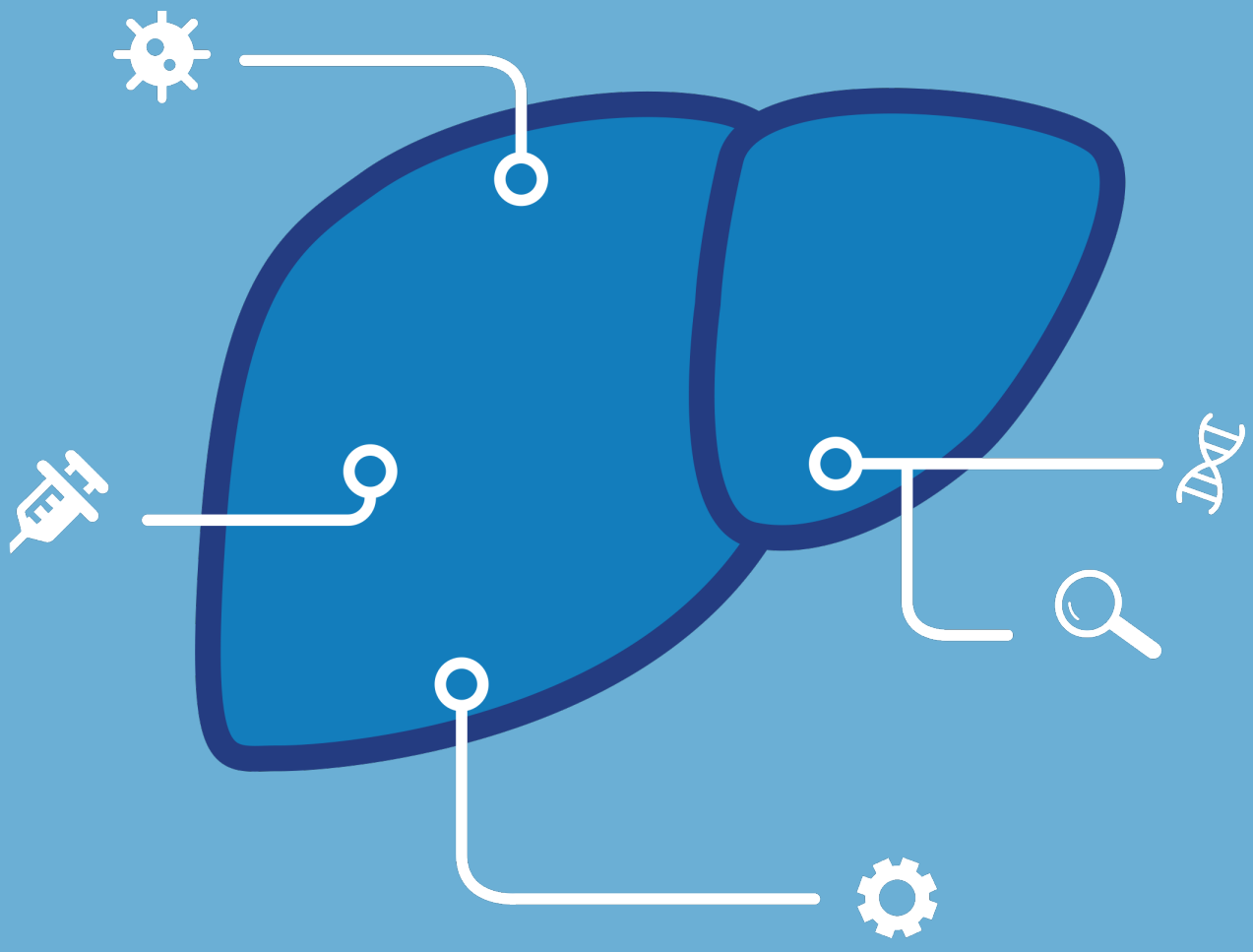
Preparing for a Liver Transplant

A Guide for Families



Boston Children's Hospital
Pediatric Transplant Center

Publication Date 6/10/2021 #167671.

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Welcome

Welcome to Boston Children's Hospital's Liver Transplant Program at the Pediatric Transplant Center. As a potential transplant recipient, your child is at the beginning of an exciting and complex journey.

At Boston Children's, we're committed to helping you every step of the way—from planning the best treatment option with you to preparing you for the challenges that lie ahead.

Your doctors, nurses and other health care professionals will work as partners with you to help you learn about your child's disease, the tests that will be done, the preparations needed before surgery, the transplant operation, the recovery period, the medications necessary for organ function and recovering at home. The members of your transplant team are your primary sources of information and are always available to answer your questions and address your concerns.

You will hear terms and words as you go through the transplant experience that you haven't heard before. You will also come across information that may be hard to understand. Building a close relationship with your transplant doctors, nurse practitioners and nurses, asking questions and using this guide will help you to become a well-informed partner with your health care team.

A transplant offers a chance for independence and better quality of life. Regular medical supervision is still needed after a transplant. This need does go down over time. It is very important to understand that transplantation is a treatment and not a cure. Potential transplant recipients must be committed to transplantation as a form of treatment in order to deal with the challenges of the treatment plan.

Receiving an organ transplant can at times be physically and emotionally draining. It can also be a wonderful experience that gives a person a new lease on life.

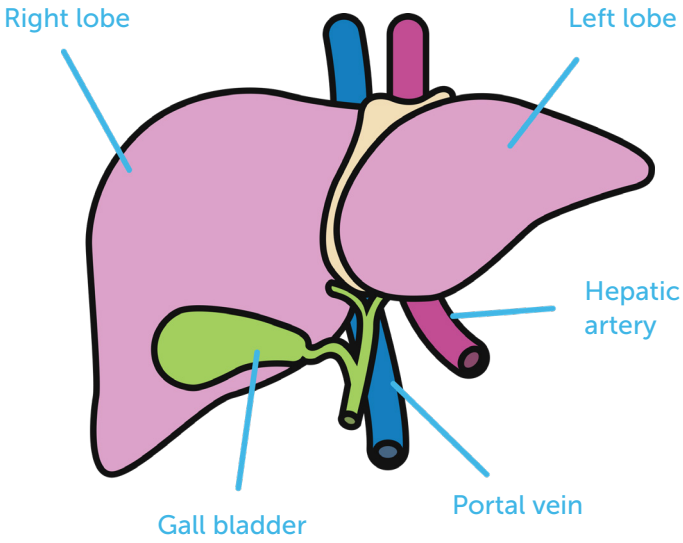
This book is made up of many sections. You'll be given a follow-up education manual when a decision has been made about your transplant evaluation.

About liver disease

Your child's liver

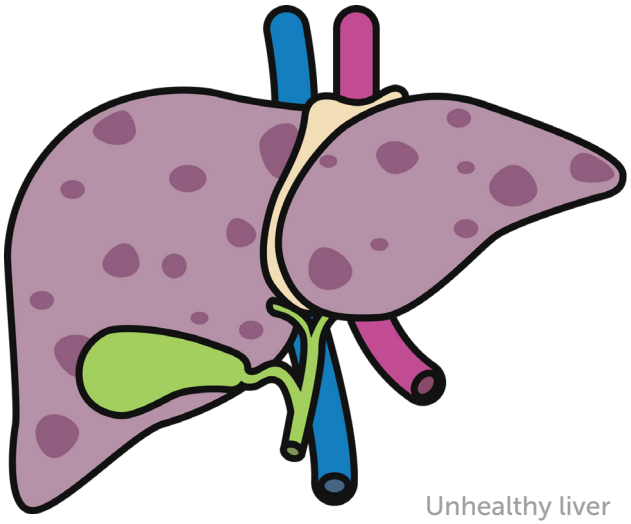
Your liver is the largest solid organ in your body. It's found near the stomach in the upper right portion of your abdomen. The liver is divided into 8 segments. These are called "lobes." It takes in blood from 2 sources: the portal vein and the hepatic artery. The portal vein brings nutrients to the liver from the intestine and the hepatic artery brings oxygen to the liver from the heart and lungs.

The liver does more than 400 different things that keep your child healthy!



The liver is a very complicated organ with many functions. These include:

- Making bile (this helps the body use protein, fat and carbohydrates)
- Making blood-clotting substances
- Using and storing minerals and vitamins
- Detoxification (taking out the harmful parts) of many substances including drugs and alcohol



Unhealthy liver

Liver disease

There are many diseases that can affect the liver's ability to work the right way.

- Poisons, alcohol, poor diet or infection may damage the liver.
- An inherited disorder may affect the liver's ability to work properly. Examples are chemical imbalances or cells and ducts that are not arranged properly (Wilson disease, biliary atresia, hemochromatosis, metabolic disorders and polycystic liver disease).
- Tumors in the liver or the bile ducts (like hepatoblastoma) can damage and even destroy the liver.
- Viral infections like Hepatitis B and C can cause the liver cells to become inflamed (swollen and tender). This can change the way the liver is shaped and destroy it.

Symptoms of liver disease

The symptoms your child may experience if your liver is not functioning properly include:

- Losing weight
- Eyes and skin becoming yellow (also called jaundice)
- Heavy itching
- Dark or tea-colored urine
- Encephalopathy (not able to focus, losing memory and/or having trouble sleeping)
- Vomiting (spitting up) blood or passing bloody stools (poop)
- Bruising easily
- Bleeding easily
- Grey, clay-colored or white stools or bowel movements
- Buildup of fluid in the abdomen (ascites) or in the legs (edema)
- Getting infections a lot

A liver transplant may be considered a treatment option for people who have advanced liver disease.

Evaluation for a transplant

Evaluation

An evaluation is needed to:

- Find out the risks and benefits of transplantation
- Catch possible problems
- Talk about choosing between a living donor and a deceased donor
- Think about the risks and benefits for possible donors

Your child will see a number of health care professionals if your child is being evaluated for a transplant. These include:

- Transplant Surgeon
- Transplant Hepatologist
- Transplant Anesthesiologist
- Transplant Coordinator/Nurse Practitioner
- Social Worker
- Pharmacist
- Dietitian
- Infectious Disease Clinician
- Financial Coordinator
- Child Life Specialist

You will be asked to bring a copy of your child's immunization records and social security number to the evaluation.

The evaluation for a transplant is usually done as an outpatient. During the evaluation, your child will be given a number of tests. These may include (but are not limited to):

- Blood tests to find out the blood type (a donor and recipient must have compatible blood), liver and kidney function tests, tests for viruses that your child may have been exposed to (like hepatitis A, B and C, the AIDS virus, CMV, EBV and/or the herpes simplex virus)
- An abdominal ultrasound or CT (these allow physicians to see the liver and flow of blood through arteries and veins)
- A chest X-ray to see if your child's lungs are healthy
- Tuberculosis testing (PPD) if this hasn't been done by the pediatrician
- Cardiac ECHO

Options for liver transplant candidates

Living donor liver transplants

Liver transplantation is the preferred treatment for many people with liver disease. But there aren't enough deceased donor livers to meet the needs of all potential recipients. A living donor liver transplant is when a section of an adult living donor's liver is transplanted into the recipient. Many transplant centers around the world use living donor liver transplantation. It has been very successful in children. Based on current data it seems that the results of living donor liver transplants are at least similar to deceased donor liver transplantation and may even be better.

Taking part of a living person's liver can be done because of the liver's unique ability to regenerate (grow back) to its normal size. A part of the liver (a lobe) can be taken out without causing any damage in liver function.

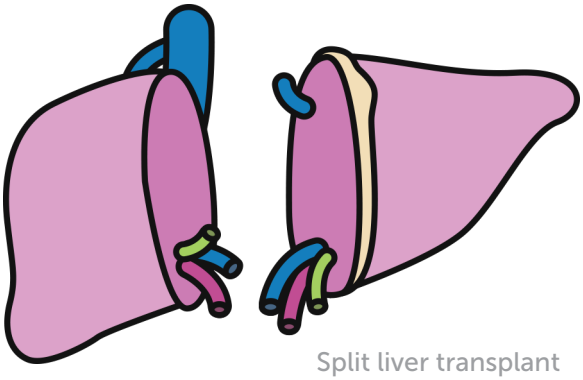
Boston Children's offers the option of living donor transplant to some people based on the kind of liver disease they have, the availability of potential living donors, blood type compatibility and liver size compatibility of the donor and recipient.

The operations are done at the same time. The donor can expect to be in the hospital for about a week. The liver of the donor and the portion in the recipient should both regenerate to normal size within 1–2 months. This is a complicated procedure that has serious potential risk for both the donor and the recipient. The decision to go ahead with this procedure is something that both people need to think about in a serious way.

The procedure is done together with the Lahey Hospital and Medical Center. The adult donor undergoes a very detailed evaluation at the Lahey Hospital and Medical Center and the surgery on the donor is done there as well. You can visit Lahey's website at www.lahey.org for more information about the Live Donor Liver Transplant process for donors.

Split liver transplants

Split liver transplants are done by dividing a deceased donor's liver so 2 recipients (a child and an adult) may benefit from 1 liver donation. The liver's unique ability to grow back to its normal size makes this possible.



Split liver transplant

Pre-transplant vaccinations

Your child is being evaluated for a liver transplant. This means that it's extremely important to give your child as many immunizations as possible before the transplant. Your child's immune system may not be able to recognize and immunize as well as normal after the transplant because of the immunosuppression medication that's needed after the transplant.

Pre-transplant vaccinations

We will make recommendations to your pediatrician regarding any vaccinations your child should receive. An accelerated schedule is also available. Some of the recommended vaccinations may include:

- **Synagis** — your child should receive Synagis monthly during November through March to protect from RSV if your child is under 24 months old and currently listed for a liver transplant.
- **PPD (tuberculosis skin testing)** — very important for this to be done before the transplant.
- **MMR (measles, mumps, rubella)** — this is a live virus and is given as 2 injections in a series. Ask your child's doctor about using it if your child has an egg allergy.
- **VZV (varicella)** — this is a live virus and is given as 2 injections in a series. It can be given at the same time as MMR.
- **DTaP (diphtheria, tetanus, acellular pertusis)** — there are 5 injections in this series. These are followed by a booster later (depending on the age of your child when the vaccination was first given).
- **Hepatitis B** — given as a series of 3 injections.
- **Hepatitis A** — given as 2 injections 6 months apart. Your child must be 1 year old or older to get this vaccination.
- **IPV (polio)** — given as 4 injections in a series (depending on the age of your child when the vaccination was first given).
- **HIB (haemophilus influenza type B)** — this is given as 3 or 4 injections in series (depending on the age of your child when the vaccination was first given).
- **Pneumococcal** — the recommended way to give this is 3 doses of the conjugate vaccine (called Prevnar) followed by polysaccharide (23-valent) vaccine.
- **Meningococcal** — this is recommended for all children over 2 years old.
- **Influenza (flu)** — this is an injection given yearly after 6 months. Ask your child's doctor about using it if your child has an egg allergy.
- **Gardasil** — this is an inactivated vaccine. It's recommended for girls as young as 9 years old (before first sexual contact). It's a 3-dose series.

Emotional and family support

Child Life

Your Child Life Specialist is an important member of your transplant team and has the expertise to:

- Support your child's development by normalizing daily routines through play
- Help your child develop ways to deal with fear, anxiety and separation
- Give individualized support before and after medical procedures
- Use developmental interventions and play to help your child and your family adjust to and understand health care experiences

Social worker

Your social worker is a very important member of the transplant team and has the expertise to help you:

- Understand the impact of your child's disease on your child, your family members and your child's friends
- Develop strategies to handle problems that come with your child needing a transplant
- Plan for financial needs

They can help you find organizations, support groups and other resources in your community for you to get the help you need. They can also set up ways to talk to others who are in similar situations.

You'll probably meet your social worker when your child's need for a transplant has been decided. You and the social worker will talk about your personal needs the first time you meet. These may include things like counseling for depression, anxiety or fears; understanding insurance coverage and other financial options; and setting up transportation to and from the hospital. Your social worker will help you figure out issues you might not even have thought about and will work with you closely to resolve them.

Financial coordinator

Your financial coordinator is a very important member of the transplant team and has the expertise to help you:

- Make the financial side of transplant care clear and understandable
- Make sure you have the ability to get medical care
- Be aware of procedure costs and approval for care (this starts with the evaluation and continues through the transplant procedure and afterward)
- Find and share alternate sources of funding

You'll need to know how to cover the costs of the transplant and medications before and after transplant while also dealing with concerns about your child's medical condition. Your financial coordinator works with your health insurance provider to figure out your coverage and benefit limits and to tell your family about options you may have.

Getting your finances in order can be a very complex process because there are so many insurance plans which all have different rules and regulations.

There are many options for transplant recipients who don't have any kind of insurance. There are also policies and laws to help transplant recipients with their special financial needs.

- Your social worker can find out what your workplace's transplant policy is if you have health insurance through your employer.
- Your financial coordinator can help you find ways to finance out-of-pocket expenses if your health plan only covers partial costs.
- Your financial coordinator can help you explore other options if you don't have health insurance. These can include state or federal funding and assistance through charitable organizations or advocacy groups.

If you are a parent with other children

The following is some advice about how and when to communicate with your other children.

- Keep siblings up to date about what's happening. Give them information they can understand. Your social worker and Child Life Specialist can help you with this.
- Keep things as routine as you can. Let them keep doing after-school activities such as sports and time with their friends if possible.
- Spend time with your other children. Doing things together like watching TV, reading or simply talking will help them understand that you love them as much as their sick sibling.
- Include all the children in the transplant process.
- Read more about supporting siblings on page 12.

Special concerns

Everyone has a different set of needs. Don't be embarrassed or afraid to bring up any topic with your social worker, your transplant doctors or nurses. They're there to help. Their wealth of experience and access to resources enables them to do a lot to make life easier for you and your family.

Spiritual needs and support

Boston Children's has a network of spiritual advisors who are can be brought in to speak with at any time. Don't forget that your own religious or spiritual community can be a source of comfort and support.

If you have other children, you are probably very concerned about how their sibling's illness is affecting them.

While you are waiting

When the evaluation is complete

The transplant team will tell you about the results of the evaluation when it's done. They'll also share these findings with your primary care physician. There are usually 3 possible recommendations:

- The evaluation has found things that make a liver transplant either contraindicated (not recommended) or not possible.
- The evaluation has found that there are other treatments or medications available that can be tried before a liver transplant.
- The evaluation has found that a liver transplant is a treatment that can be done.

The liver transplant team will work closely with you and your child's physicians in all of these cases to put together a coordinated care plan. You'll also be given a notification of the decision in writing.

Listing for a transplant

The next step after you and your doctors decide that a liver transplant is the most appropriate treatment option is that your child will be "listed" as a potential transplant recipient on a national computer system called the United Network of Organ Sharing (UNOS). UNOS uses weight and blood type to match organ donors with children waiting for a transplant. The wait can be from days to months to a year. It depends on blood type, weight and how serious the illness is. You should make transportation plans so you can get to the hospital quickly if this is needed. All families are required to fill out a contact sheet so that we can reach you at any time if an organ becomes available. (See the appendix in this book for the form to fill out.)

The goal during listing and waiting is to support your child's current liver function and to make sure your child has the best quality of life possible. We'll work closely with you and your child during the waiting time. Your child will have regular hospital visits for check-ups. These include physical examinations and blood work.

Children and adolescents have generally done well emotionally with this waiting period. There's no question that it's stressful for them to wait and wait and not know when (or if) the transplant may happen.

Parents tell us about that same stress. We also hear them talk about what it means to wait for another child to die so that their child may live. The liver transplant team is ready to support you and your child during this waiting period. Our social worker, Child Life Specialist and child psychiatrist or psychologist are also available and will check in with your family as needed.

Program coverage plan

- The Liver Transplant Program has surgeons and physicians available 365 days a year, 24 hours a day and 7 days a week to provide program coverage. A transplant surgeon or transplant physician will be readily available to manage organ acceptance, procurement (picking up and delivering) and implantation as well as to address urgent issues.
- We will let you know if there are any large changes to our Program Coverage Plan. These may include changes in medical or surgical directors.

Program statistics

Our program-specific patient and graft survival statistics are provided with this handout. These statistics are compared to the national averages within the chart provided. Please refer to the accompanying folder for this information.

How are organs allocated?

The United Network for Organ Sharing (UNOS) is responsible for transplant organ distribution in the United States. UNOS oversees allocation (finding and keeping track) of many different types of transplants including liver, kidney, pancreas, heart, lung, intestine and cornea.

UNOS gets data from hospitals and medical centers throughout the country regarding adults and children who need organ transplants. We are responsible for sending the data to UNOS, and updating them as your child's condition changes. Rules and measures have been laid out to make sure that all people on the waiting list are judged fairly as to the seriousness of their illness and the urgency of getting a transplant. Once UNOS receives the data from local hospitals, people waiting for a transplant are placed on a waiting list and given a "status" code and a PELD (if under 12 years of age) or MELD (if the child is 12 years of age or older) score. The people in most urgent need of a transplant are placed highest on the status list (Status 1A or 1B) and are given first priority when a donor liver becomes available.

A PELD (Pediatric Model for End-Stage Liver Disease) score is a scale that can predict the risk of dying from liver disease very accurately within three months for pediatric patients waiting on the transplant list. The PELD score uses levels of bilirubin, albumin, INR and sodium along with growth failure. A MELD (Model for End-Stage Liver Disease for older children and adults) score is the same scale as the PELD but it uses bilirubin, INR and creatinine only. You can find more information about PELD and MELD by visiting the UNOS website at www.unos.org or requesting a brochure about it by calling 1-888-894-6361.

UNOS also offers a patient services line to help transplant candidates, recipients and family members understand organ allocation practices and transplantation data. You can also call this number to talk about a problem you may be having with your transplant center or the transplantation system in general.

A computer searches all the people on the waiting list for a liver when a donor liver becomes available. It rules out those who are not good matches for the available liver. A new list is made from the candidates who are left. The person at the top of this list is considered for the transplant. If this person is not a good candidate for some reason then the next person is considered, and so on. Some reasons that people lower on the list might be considered before others at the top include the size of the donor organ and the distance between the donor and the recipient.

UNOS requires transplant centers to tell every person waiting for a transplant that listing at multiple (more than 1) centers is allowed. We provide written information to all patients about multiple listing and transferal of waiting time (see the blue information folder for this brochure). For more information you can contact UNOS directly at www.unos.org. Transplant recipients are responsible for finding and/or contacting other centers. We can offer help if needed.

Helping children cope when a sibling has health care needs

Sometimes siblings may have troubling feelings such as sadness, worry, anger or guilt when a child in a family has health care needs. Parents can think that this may be their fault. This is not the case. It's normal to have many feelings at the same time. It takes time to work through feelings and these feelings may remain even after your child comes home from the hospital. The Child Life Specialist can help your family with this.

Below is some information for helping siblings when 1 child is ill or has special health care needs.

Some ways feelings are expressed

Children often don't know how to talk about their feelings. They express themselves in other ways. These can include:

- A change in eating habits
- Becoming more quiet than usual
- Spending time alone or away from family members
- Trying very hard to please parents or other grown-ups
- Acting out by not listening, fighting or even hitting others
- Looking for affection more than usual
- Moving back to younger behaviors, like bed wetting, baby talk or thumb sucking
- Saying that they feel sick or acting like they're sick

Siblings may feel:

- **Sad** — they miss you and the sick child.
- **Lonely and left out** — this may happen when they're spending more time than usual away from their parents. They may feel left out if no one tells them what is happening.
- **Worried and afraid** — about you and afraid of what's happening to their sick sibling. They may believe everything is changing and won't ever be the same again. They sometimes worry that they or their parents may get sick too.
- **Guilty** — thinking they may have caused the illness because they did something mean or had a mean thought. They may worry that their sibling's illness is their fault. They may also feel guilty because they are healthy and can do things their sibling can't do.
- **Jealous and angry** — because of all the attention being given to the sick child. They may act out their anger by not following rules or fighting with others. They may complain of feeling sick to get more attention.
- **Confused** — because they don't know what's happening now (or why) and what might follow.

Ways you can help

- Talk together as a family about what's happening and why the child is sick. Give simple and honest explanations at your child's developmental level.
- Tell siblings that it's important to ask questions and that you'll either answer them or find out the answers.
- Tell your child that you understand how hard it is to be going through this experience. This can help your child understand that their feelings are normal.
- Encourage siblings to talk about their feelings. Let them know that it's okay to cry, to be angry or be happy and to have many different feelings.
- Keep daily routines as normal as possible. This includes going to school, meals, naps and bedtimes.
- Give your other children special attention whenever possible.
- Bring siblings to visit the hospital when possible. Talk with staff about how to prepare for a visit. Plan these visits according to your child's interest and comfort level. You can set up phone or video calls if a visit isn't possible.
- Suggest that siblings draw pictures or make cards to send to the hospital.
- Tell teachers and daycare providers about the changes at home.
- Look for support from family and friends. Ask hospital staff about ways to find support for yourself and your family.

Other kinds of help

There are many people in the hospital who can help you and your family. There are Child Life specialists, nurses, social workers, psychologists, doctors and nurse practitioners who can answer your questions, suggest books to read and help you learn ways to talk to your other children.

Books for preparing

Suggestion: When reading to children ages 2 to 3, point out the pictures and talk about your family's story in simple terms. When reading to children ages 3 to 6, read the book and talk about your family's story.

A Visit to the Sesame Street Hospital

- Random House, Inc., New York 1985
- Recommended for ages 2 to 6

Grover learns that he needs an operation; he goes on a hospital tour with his mother and Sesame Street friends to explore the hospital.

Going to the Hospital by Fred Rogers

- PaperStar Book: The Putnam & Grosset Group, New York 1997
- Recommended for ages 3 to 8

Uses real-life pictures of children, parents and hospital staff and describes different parts of a hospital stay.

Fat Dog's First Visit: A Child's View of the Hospital by Charlotte Bokal Krall & Judith Mager Jim

- Pritchett & Hull Associates, Inc., Atlanta, Georgia 1987
- Recommended for ages 6 to 8

A little girl comforts her favorite nighttime toy and talks about going to the hospital by describing what their hospital stay will be like.

Tubes in My Ears: My Trip to the Hospital by Virginia Dooley

- MONDO Publishing, Greenvale, New York 1966
- Recommended for ages 6 to 10

Luke undergoes surgery for placement of ear tubes. Children about to undergo any kind of surgery will enjoy learning from Luke as he tells his story.

The Moonballoon: A Journey of Hope and Discovery for Children and Families by Joan Drescher

- Association for the Care of Children's Health, Bethesda, Maryland 1966
- Recommended for ages 7 to 12

This interactive book gives children the opportunity to create their own stories of hope and discovery about their health care experience.

Why am I Going to the Hospital? by Claire Ciliotta & Carole Livingston

- Carol Publishing Group, Secaucus, New Jersey 1992
- Recommended for ages 8 to 12

A child takes the reader through a step-by-step journey describing fact and feelings related to a hospital stay.

Your Child in the Hospital: A Practical Guide for Parents by Nancy Keene & Rachel Prentice

- O'Reilly & Associates, Inc., Sebastopol, California 1997
- Recommended for adults

Helps parents prepare a child both physically and emotionally for a hospital experience including an outpatient test or overnight stay.

Preparing your child for hospitalization or a procedure (test)

Telling your child about going to the hospital

A child's understanding of the hospital or a procedure is based on their personality, language development and ability to understand information. Below are some age-related guidelines that may help you. Keep in mind that children develop at different rates and these guidelines may not describe your child exactly.

Newborns - age 2

When your child is very young, you can concentrate mostly on preparing yourself for the hospital. Children are usually able to sense when their parents feel comfortable and react in the same way.

Ages 2-3

Children at this age don't understand time in the same way as older children and adults. Talk with doctors and nurses about how you think your child will manage best in the hospital setting. You can think about whether it might be best to tell your child about their operation or procedure 1–2 days before going to the hospital.

Ages 3-6

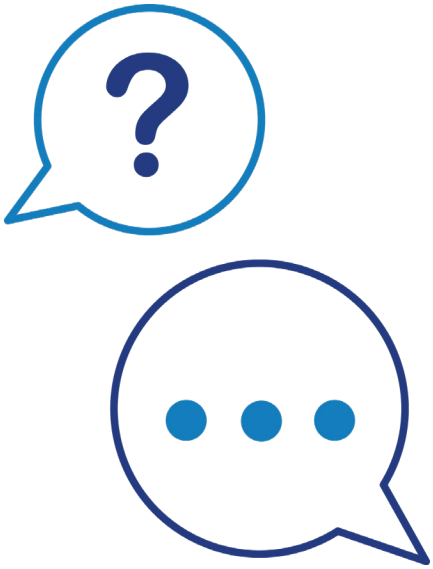
Children at these ages are beginning to learn about the days of the week and are getting a sense of time. It can be hard for a child to understand why they need an operation or procedure. Your child may worry that they've done something wrong. Reassure them that the hospital stay is about having something fixed and is never a punishment. Use simple and short explanations. Think about telling your 3- to 4-year-old about an operation or procedure 1–2 days before. Think about telling your 5- or 6-year-old 3–5 days ahead of time.

Ages 7-11

Children at this age are able to understand the reason for a hospital stay or procedure and have also developed a sense of time. You may want to tell your child about their operation or procedure 7 days beforehand. This will give them plenty of time to ask questions and to talk about any worries they may have.

Age 12 - adult

It's best to include this age group from the beginning in planning for an operation or procedure. Encourage them to ask questions and to talk about any worries they may have. Most children at this age are struggling for independence from their parents while at the same time seeking their support. You may want to ask how you can help them through the hospital stay or procedure.



Talking with your child about the hospital

Children usually sense how a parent feels about a hospitalization or procedure. It's important to let your child know that you feel that it's the right thing to do.

- Choose a quiet time to talk.
- Use a calm and relaxed voice.
- Ask what your child knows or thinks about the hospital. Start with what your child seems to be most focused on at the moment.
- Use honest and simple explanations.
- Use words and pictures that your child is familiar with when possible.
- Tell your child as much as possible about the hospital.
- Tell your child how long the hospitalization, test or procedure will last.
- Reassure your child that you will always tell them what's going to happen ahead of time. This is especially good for your child to know if it might be something scary like a shot. This will give your child a feeling of trust.
- Try to use words that are neutral when you talk about procedures or tests. You can use words like "slide" instead of "poke" when talking about a needle.
- Try not to make promises that you can't keep. Don't tell your child that nothing will hurt.
- Tell your child how they may feel before, during and after the operation, procedure or test. You may want to explain that they will not hear anything during the operation.
- Tell your child about any plans for an overnight hospital stay. Let your child know that you'll be able to sleep at the hospital so you can be near them. Encourage your child to pick out some favorite toys to bring.
- Tell your child that friends and family will be able to visit.
- Encourage your child to ask you, the doctors and the nurses any questions they have at any time.
- Ask your child questions to make sure they understand what you've told them.
- Let your child know that it's okay to feel many different ways about going to the hospital.
- Listen to your child's feelings and help your child talk about them.

Getting your child ready for the hospital

Find ways to help your child cope with a difficult situation, painful or frightening procedure.

Things children can do

- Breathe deeply.
- Blow bubbles.
- Pretend to blow out candles.
- Think about a happy or fun time and pretend to be there.
- Count backwards.
- Squeeze your hand.
- Listen to music.
- Look at a picture or toy.

Things parents can do

- Tell your child what to expect.
- Use a calm, soothing voice.
- Reassure your child.
- Give encouragement.
- Hold your child's hand.
- Stroke your child's face or arm.

Getting support

You may want your child to see a counselor if they seem unusually worried and/or frightened. The Boston Children's Coping Clinic provides evaluations, treatment and support for children and families. You'll meet with a psychologist or psychiatrist to discuss your concerns, ask questions and learn more about how to help your child.

You can make an appointment by calling 617-355-6688.

To learn more about preparing for the hospital and/or other health care topics: Call the Center for Families at 617-355-6279.

Email centerforfamilies@childrens.harvard.edu.

Preparing yourself for your child's health care experience

Preparing for a child's hospital stay or procedure can affect many areas of daily life. In addition to rearranging regular activities you may experience many emotions. It's just as important to prepare yourself as your child. Giving yourself time to experience your own feelings will help you better support your child.

Ask questions

- What should I tell my child about the procedure or operation?
- What will happen immediately before the operation or procedure?
- How long will the procedure or operation take?
- May I stay with my child during the procedure?
- Where will I wait during the procedure or operation?
- When will I be able to see my child afterwards?
- How will my child feel?
- Will my child be in pain?
- How long will my child stay inthe hospital?
- How long will it be before my child can go back to school and play?
- Where can I find more information on my child's condition?

Learn about the hospital

- Learn about the medical equipment that your child will need in the hospital.
- Take a tour of the surgical waiting area, procedure and hospital rooms.
- Meet staff members on your child's unit and learn about their roles.
- Learn about the hospital and staff routines.
- Ask for a booklet about the hospital.

Tell staff about your child

Remember that you know your child best. Be sure to tell your child's doctors, nurses and other caregivers about your child's personality and past experiences with health care. Staff can often find ways to make the experience less upsetting.

Take care of yourself

- If possible, take turns with another caregiver in sleeping at the hospital; make a schedule before your child is admitted.
- Take breaks—go for a walk, a cup of coffee. Ask the Child Life specialist if a volunteer can stay with your child.
- Talk with other parents who have been through similar experiences; talk with friends and family about your worries and concerns.
- Learn deep breathing and relaxation exercises. Programs are shown on Channel 28 (the hospital's Education & Relaxation channel).
- Exercise regularly. Stop by the Center for Families or ask your social worker or Child Life specialist about using the gym near the hospital.
- Ask about a parent coffee hour; ask about support groups.
- Keep a journal about your hospital experiences.
- Plan time to see your other children.
- If you and your child's other parent are not together but are both part of your child's life, take time to decide who will be with your child at different times. Let your child know the plan.
- If you have a restraining order against your child's other parent, bring a copy with you and show it to the social worker.
- If you are worried about domestic violence issues, call AWAKE (Advocacy for Women and Kids in Emergencies) Program, or speak to a nurse or social worker.

Your child's health care team

Boston Children's is a teaching hospital. This means that doctors, nurses and other health care professionals who are in training may care for your child. Each staff person in training works under the supervision of a qualified senior professional. Boston Children's believes that all these staff members add to the quality of your child's care.

Some members of the team include:

- **Attending Physician** — a senior staff medical or surgical doctor who directs your child's care
- **Fellow** — a medical doctor in training who specializes in one area
- **Resident** — a medical doctor who is training in pediatrics
- **Pharmacist** — works closely with the transplant team to develop a medication plan specific to your child. Educates you and your child on medications and their side effects.
- **Nurse Practitioner** — an advanced practice registered nurse with special training in diagnosing, treating and caring for patients
- **Staff Nurse** — a nurse who takes care of your child throughout the day and night. There is always a staff nurse responsible for your child's care
- **Dietician** — a health care professional who monitors caloric intake of your child and assists with optimizing your child's food/formula
- **Clinical Assistant** — a person trained to assist the staff nurse
- **Child Life Specialist** — helps children find ways to express themselves through play and other activities
- **Chaplain** — can bring spiritual support and companionship at a difficult time
- **Social Worker** — a health care professional who meets with families to help them better cope with illness and hospitalization
- **Financial Coordinator and Resource Specialist** — helps families find resources in the hospital and the community, such as short-term housing and transportation
- **Case Manager** — a nurse who follows your child's care from before the admission to after discharge. They will keep your insurance company informed of your child's progress during hospitalization and will help to arrange for any home care services your child may need.
- **Psychiatrist or Psychologist** — a doctor who works with parents and children to help them learn ways to manage and cope with feelings

Services available to you

- **Inpatient business office:**

  617-355-7086

  Located on the first floor next to the cashier's window. Staff members are available to help you with questions about your bills and health insurance.

- **Outpatient financial center**

  617-355-5999

  Located in the Fegan Lobby on the first floor near outpatient registration. Staff members are available to help you with questions about bills and health insurance.

- **Hale Family Center for Families**

  617-355-6279

  Provides information for parents and families on many topics, such as health and health care, community services, support groups and safety issues.

- **AWAKE (Advocacy for Women and Kids in Emergencies)**

  617-355-6369

  If you are in a relationship that may be abusive and would like to talk with someone confidentially, an AWAKE advocate will listen and offer assistance. Ask for the AWAKE advocate on call.

- **Lactation Support Group**

  617-355-6279

  Has a specialist who works as part of the health care team to promote and support breastfeeding.

- **Family-to-Family Program**

  617-355-6279

  Offers support to families by connecting them with trained, experienced volunteer families whose children have similar needs.

- **Pastoral Care**

  617-355-6664 or 617-355-6369

  Has trained staff to meet with families and help with spiritual needs. Ask for the chaplain.

- **Children's Coping Clinic**

  617-355-6688

  Evaluates, treats and supports children and families facing hospitalization and other health care concerns.

- **Interpreter Services**

  617-355-7198 or 617-355-6369

  More than 40 professional interpreters are available for families and patients who do not speak English or do not feel comfortable with medical terms in English. Ask for the interpreter on call.

- **Concierge Services**

  617-355-8992

  Assists families with non-medical needs before, during and after a visit to the hospital. Services include overnight accommodations and travel arrangements, car rentals and other requests.

At the hospital

It's very important that we are able to get in touch with you at any time. Please make sure that we have correct and current home phone and cell phone numbers. It's also very important that your travel arrangements are in place well before you get the call to come to the hospital. This will help make sure that valuable time is not lost when you make your way to Boston.

When you get the call to come to the hospital

When you get the phone call from the transplant center to come to the hospital:

- Ask about any medications your child should take before you come to the hospital.
- Let us know if your child has a temperature or is currently sick.
- Do not allow your child to eat or drink **anything** after you get the call.
- Be ready to leave the house within **1 -2 hours** of getting the call.
- Keep in mind that you could be sent home and the transplant could be cancelled if the transplant program discovers a problem with the new organ or finds that your child has a condition that could put your child's health or the transplant success at risk.
- Bring your transplant binder to the hospital with you.
- Please bring your child's insurance information with you.
- Make your way to the hospital **safely!**
- You'll be told where to go when you arrive. If you arrive between 7:30 a.m.-7:00 p.m., you will probably go right to Admitting/Pre-Op on Main 2. If you arrive after 7:00 p.m., you will probably go directly to 10 South in the main building.
- A nurse will take your child's vital signs, perform a physical assessment and interview you regarding their history when you get to 10 South.

The operation

A donor liver can become available at any time of day or night. Timing is extremely important: **You need to get to Boston Children's as soon as possible.** Things may happen very quickly because we often need to have your child ready to go to the operating room within hours of your arrival. It's very important to plan ahead so you can be ready if/when the call comes.

Your child will be admitted to the Solid Organ Transplant Floor (10 South) to be prepared for surgery. An intravenous line will be placed and blood tests will be done. You and your child will be seen by the surgeons and anesthesiologists to talk about the upcoming procedure and sign consent forms.

A surgical team will be leaving to pick up the donor liver at the same time your child is being prepared for the operating room. The time of the operation is planned to match the surgical team's arrival back at Boston Children's. The liver can't live long outside the body. This means that it's urgent to get it to our hospital and transplant it within a few hours.

It's possible that the surgical team may decide that the donor liver is not a good match after all. Your child's surgical procedure **will not be confirmed** until the team is at the donor hospital for this reason. This means that your child's surgery may be cancelled even after receiving medication and having blood tests. You'll return home and wait for the next liver assignment if this happens.

The transplant operation involves taking the damaged liver out of your child's body and attaching the new liver. The transplant operation takes about 6–12 hours. Each operation is different. You'll be told about the details of your child's operation.

You can wait in the Medical Surgical Intensive Care Unit (MSICU) waiting room on 7 South or in the main surgical waiting area on the third floor of the main building. You'll be given progress reports every few hours during the operation.

After the operation

Your child may return from the operating room on a ventilator (breathing machine) with a breathing tube in the nose or mouth. Your child will be on a cardiac monitor, have several IVs, tubes coming out of their abdomen and a large dressing (bandage). There will be many kinds of equipment attached to your child. Your child will be in a single room in the MSICU to keep them from getting an infection.

You'll need to wash your hands or use hand sanitizer each time you enter or leave your child's room. Visitors are limited to parents and immediate family during the time right after the operation.

Information about tubes, drains and monitoring

Breathing tube (ET tube)

The tube that was placed in your child's throat and attached to the respirator helps them breathe. It may still be in place when your child wakes up. Fluid from your child's mouth and the tube will be removed often with a suction catheter while the breathing tube is in place. Your child will not be able to speak while this tube is in place. The nurse can help your child communicate.

The tube will be taken out when the team has decided that your child's lungs can work well enough without help. They will decide this by taking a chest X-ray and blood samples to measure the oxygen in your child's blood. Your child may have a mild sore throat and/or hoarse voice after the tube is taken out. This should go away in a couple of days.

Nurses will encourage your child to cough and breathe deeply very often after the tube is taken out. This is done to keep the lungs clear of fluids and keep oxygen flowing freely. Respiratory therapists and your child's nurses will help keep the lungs clear by doing chest PT (gentle tapping of the lung area) and using a spirometer (a device that helps your child breathe deeply) or blow bubbles. This is done to keep fluid and secretions from building up in the lungs. A lung infection or pneumonia can happen if this is not done.

Naso-gastric tube (NG tube)

A NG tube will be inserted through your child's nose and into the stomach in order to keep the stomach empty. The tube will be taken out when bowel sounds return or when your child passes gas (flatus).

Intravenous lines

The intravenous (IV) lines may stay in place for all of your child's hospital stay. They allow nurses to draw blood for tests, give medications and provide fluid that helps the blood circulate. They are also helpful in closely watching heart and lung function.

Foley catheter

This tube is placed into your child's bladder while they're asleep in the operating room. It's used to drain urine. It's usually taken out a few days after surgery.

EKG leads

These leads (thin wires) allow your team to closely watch your child's respirations and heart rate.

The Jackson-Pratt (JP) drains

The transplant surgeon places JP drains around your child's new liver. They will usually be taken out 1 at a time during the admission.

Biliary tube

The transplant surgeon may place this tube in your child's bile duct. It helps the team closely watch how well the liver is working and how well the bile ducts are healing. It's often attached to a bag to drain the bile. Your child will have a cholangiogram (special fluid injected into the tube to study the bile duct area) within 6 weeks of their transplant operation. It is a non-painful procedure that takes only moments. The biliary tube is usually taken out in the outpatient clinic about 6 weeks after the transplant.

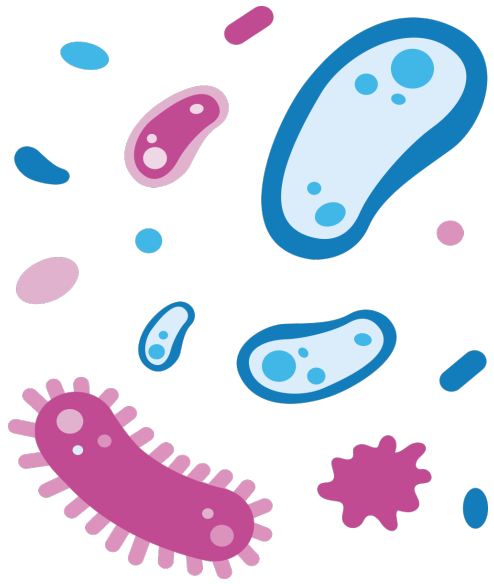
Possible complications after the transplant

Rejection

Rejection is a signal that the immune system has seen the new liver as foreign tissue and is trying to attack it. Keeping rejection from happening by using immunosuppression (weakening the immune system) medications is the first priority. An episode (1 time) of rejection of the transplanted liver is very common.

Your child's liver function tests will be watched very closely because most people will not have signs of rejection that are easily seen.

A biopsy may be done to double-check that your child is having a rejection episode if the tests are not normal. The amount of your child's anti-rejection medication is raised or a different combination of anti-rejection medications is prescribed if your child has a rejection episode. Adjusting medications will stop rejection in more than 95 percent of these cases.



Infection

Anti-rejection medications "tell" your child's immune system to accept the new liver.

This means that they also can be telling the immune system to accept other things that it would ordinarily fight. In other words, the anti-rejection medications put your child at risk for getting an infection. The most common infections come from viruses that were already dormant (not active) in your child's system or in the donated liver. Your child will take anti-bacterial, anti-virus and anti-fungal medications for many months after the transplant in order to keep infection from happening.

Your child's team may take sputum, blood and urine samples as well as samples from your child's catheter, wound and drain sites if an infection is suspected.

If your child gets an infection, it will be treated with medications special for that infection.

If an infection happens after your child goes home from the hospital, it's usually treated as an outpatient (not coming back to the hospital) with antibiotics. Some people do need to be readmitted to the hospital for treatment with IV medications.

Primary graft non-function

On very rare occasions a new liver doesn't work the right way after the operation. A second transplant operation is urgently needed when this happens.

Bile duct complications

The new bile duct that was connected during surgery may leak or become blocked after the operation. A cholangiogram might be done if this happens. A cholangiogram is done by injecting X-ray or contrast dye into the tube to see if there are problems. Most bile duct problems can be treated without further surgery. Some problems do require another operation.

Vascular complications (problems with blood vessels)

On rare occasions there may be problems with the new connections between the veins and arteries of the new liver and those in your child's body. Laboratory tests, ultrasounds and X-rays help your child's team see if there are any problems like this. Surgery is sometimes needed to correct these problems.

Bleeding

Bleeding from your child's incision or in the gastrointestinal tract is a possible complication that can be managed if it's discovered and shared quickly. Report any bleeding to your child's doctor immediately. The kinds of bleeding you should report include:

- Bleeding from the incision
- Vomiting blood
- Blood in bowel movements

Post Transplant Lymphoproliferative Disease (PTLD)

Children who are given immunosuppression medication for organ transplants may develop a disorder in which lymphocytes (one kind of white blood cells) start growing abnormally (not normal). This is usually triggered by Epstein-Barr virus (EBV). EBV infects B-cells (a kind of lymphocytes). These abnormally growing cells may be found in lymph glands anywhere in the body or in organs like the intestine, the spleen and even the new liver itself.

Lowering the amount of immunosuppression medications can reverse the early stages of PTLD but sometimes other treatments are needed. PTLD can build up to become lymphoma (cancer of the lymph cells) which means that chemotherapy and other medications may be needed. This is rare.

Your child's risk of this happening depends on their history of EBV infection and the kind of immunosuppression medications needed. Your child's doctor will talk with you about this risk and how the team looks out for any signs of it happening.

Hospital stay

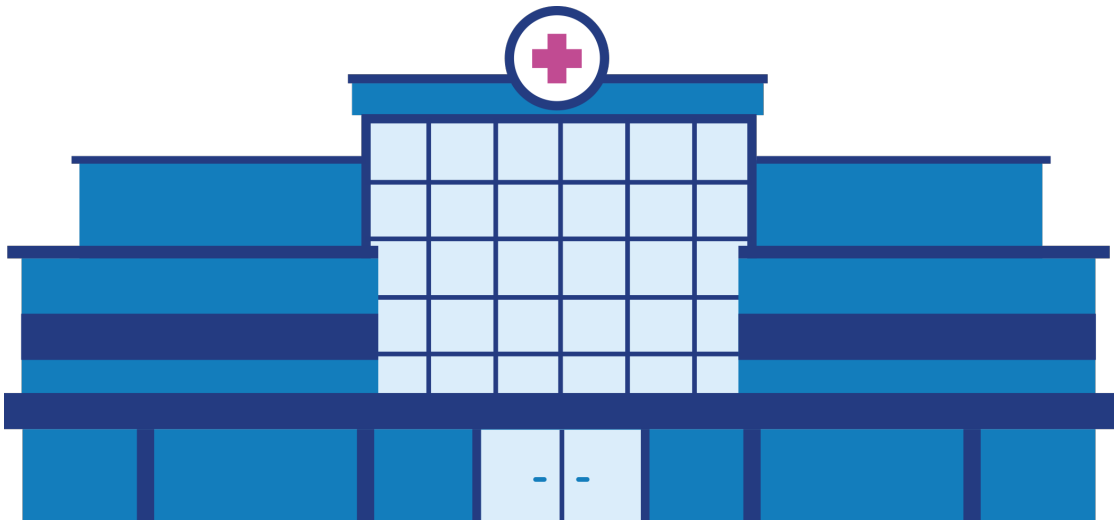
The average hospital stay for a liver transplant is 10-21 days. The exact timing depends on your child's age and size. A few days are spent in the MSICU. The rest are spent on the Solid Organ Transplant Floor. Patients go to a single room on the floor when they leave the MSICU. Your child will continue to recover and be closely watched for rejection, infection and other problems. Medications will be adjusted often.

While you're on the transplant unit you can encourage your child to cough and breathe deeply to keep the lungs clear of fluid. Encourage your child to get out of bed and walk around the unit at least 3 times a day. Walking helps boost blood circulation, cut down on gas pains and support muscle tone.

Your child will also be seen by the unit's Child Life Specialist and social worker to provide additional support and help with coping during the time in the hospital. You'll begin to learn about the medicines and care your child will need at home. Our goal is to have each family feel comfortable and confident with every part of their child's care before they leave the hospital.

The transplant unit after surgery

You'll learn how to care for your child after you leave Boston Children's when your child leaves the ICU. You'll have many things to remember when you go home. Taking an active role in your child's care while in the hospital will help you provide better care when you get home. Your role as a partner with the transplant center becomes more important than ever at this point because your child's new liver will need lots of care, attention and close watching to do its job. Having a transplanted liver is a lifelong commitment.



Medications

Your transplant team will decide on the right medications for your child. You'll be given the exact medication information for your child once your child is listed for transplant. A brief summary is included here.

After the transplant, most children are on medications which include (but are not limited to) the following:

- Anti-rejection medication (Tacrolimus) that your child will take for as long as your child has a functioning organ
- Medications to:
  - Control blood pressure (Norvasc) as well as protect your child's kidneys
  - Keep infections from happening (Atovaquone, Nystatin, Valganciclovir/ Acyclovir)
  - Keep thrombosis from happening (aspirin)
  - Protect the stomach from acid (Protonix/ Prevacid)

You'll meet with the transplant pharmacist regularly to go over medications, side effects, storage guidelines and other key information for each medication. You'll be asked to point out and name each medication and talk about their usage and side effects while at the hospital.

It's also crucial (extremely important) to know the dosage for each medication in both milligrams and milliliters or have a written sheet available at all times with this information. This is because many of the medications come in different strengths. Not knowing the milligrams/milliliters could lead to a medication error which could be harmful to your child.

By taking responsibility for your child's medications while at the hospital (under the supervision of a nurse) you can make the transition to home less stressful.

Notes

Boston Children's Hospital
Pediatric Transplant Center

Family Education Guide