

What Every Parent Needs to Know

A guide when your child needs a transplant





Who are UNOS and the OPTN?

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that manages the nation's transplant system – known as the Organ Procurement and Transplantation Network (OPTN) – under contract with the federal government. The OPTN helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants. All transplant programs and organ procurement organizations throughout the country are OPTN members and are obligated to follow the policies the OPTN creates for allocating organs.

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Dear Parents,

When you get the news that your child needs an organ transplant, you may react with shock or surprise. Dealing with a child's sudden or chronic illness can be difficult for any family. You will have many questions, and you may not know where to find answers.

The most important thing to know is that you are not alone. In fact, we want to be part of your support group! We are parents of young organ transplant recipients, and we worked with experts in the transplant field to create this guide. It explains the transplant process from a parent's viewpoint, and it brings up issues you and your family may face before, during and after the surgery. This guide serves as an overview and a place to start. Reach out to your transplant team as you continue on this journey.

We started this project by asking transplant parents a simple question: What is one thing that you know now that you wish you had known in the beginning? We received many responses through social media and other sources. We did our best to provide answers, and to point to trusted resources that worked for us. We address issues for infants, toddlers, teens and in-between. We tried to focus on topics we found to be important. We also know that each transplant journey is unique. Your doctors and transplant team are the best source of information about your child's case.

This guide has two sections. The first section walks you through the transplant process from the time you learn that your child needs (or may need) a transplant. We cover many issues parents and families may face before and during the transplant. These include financial concerns, explaining to your child how deceased donation works, and other important issues. The second section offers tips to help you and your child manage life after the transplant. There are many new concepts to learn, so we define terms and point to online and print resources you can consult.

Here is one term that you may want to know up-front: A **pediatric patient** is a transplant candidate placed on the U.S. transplant waiting list before their 18th birthday.

If you have more questions or suggestions to improve this guide, we welcome your feedback! You can contact us at unoscommunications@unos.org. And if this guide is helpful to you, please let other parents know about it.

Kind regards,

U.S. Organ Procurement and Transplantation Network (OPTN) Patient Affairs Committee (PAC), working with members of other OPTN committees and staff at **United Network for Organ Sharing (UNOS)**.

Section 1

Before and during the transplant



The Transplant Process

Your child needs a transplant. What now? The path to organ transplantation is a journey. Your family's transplant journey may begin when your doctor tells you that your child needs an organ transplant, or when you find out that your child suffers from end-stage organ disease.

There are seven basic steps in the process before and during the transplant. The process continues after the transplant, which we cover in Section 2.

1. Find a transplant center
2. Get to know your transplant team
3. Transplant evaluation
4. The waiting list
5. Waiting for a match
6. The call (organ offer)
7. Transplant surgery

Each of these steps is unique to your child's condition. Your child may have a chronic illness in which a transplant is planned for months or years. Or your child may have an acute illness and need an emergency transplant within days or weeks. In these cases, the first steps may be compressed and require quick decisions with the support of the transplant team.



1. Find a transplant center

A **transplant center** is a hospital with health-care providers who specialize in all aspects of transplant medicine. All transplant centers in the United States are part of the Organ Procurement and Transplantation Network (OPTN). Not all hospitals perform transplants and not all transplant hospitals do pediatric transplants.

Your child's doctor can refer you to a transplant center that

- Specializes in your child's medical condition,
- Is most conveniently located for your child's and family's needs, and
- Will work with your insurance.

Go to the **Scientific Registry of Transplant Recipients (SRTR)** website (srtr.org) to find and compare transplant centers. You can search for U.S. transplant centers by organ and Zip code. You can see how many transplants they performed and compare outcomes for adults and children who received transplants at a particular center.

If you have concerns about your transplant center, you have a right to get help or even a second opinion. Feel free to call **UNOS Patient Services** at 888-894-6361 if you would like to discuss your options with a patient services representative.

2. Get to know your transplant team

The transplant team will oversee your child's care. Team members will help you take care of your child's health issues, identify and create your support system, and work on your financial plan. Each transplant center is different, and so are the team members. These are some of the roles that you may find.



At the time of my daughter's first transplant, it would have been nice to be able to talk to another parent going through it.

—Heather Snow, liver recipient parent



Transplant coordinator

- Assists and guides you and your family through the transplant process.
- At most centers, is your family's point-person.
- Helps you meet requirements to add your child to the transplant waiting list.
- Works with OPOs to review organ offers and plan your child's transplant.

Transplant doctors and nurses

- Manage your child's care and arrange for tests.
- Clinical nurse specialists can provide you and your child with specific transplant information.

Transplant surgeon

- Performs the operation when an organ is available.

Transplant administrator

- Works behind the scenes to manage the team.

Social worker

- Can help you find support and services during your child's hospital stay.
- Can provide letters for work or school, if needed.

Psychologist

- Can help a child find ways to cope and reduce stress during the transplant process.
- May also work with a child on taking medications (particularly during teenage years).

Transplant pharmacist

- Works with your doctors and discusses with them your child's transplant medications.
- Can help you figure out how to ensure your child takes all required medications.

Registered dietitian nutritionist

- Cares for the patient before, during and after transplant.
- Develops nutrition support regimens (tube feeds and IV nutrition), and vitamin and mineral supplementation.
- Good nutrition status is vital for a successful transplant

Financial coordinator

- Helps you create a plan to cover costs before, during and after your child's transplant.
- Can advise you on insurance issues, help you find financial aid, and explain copay charges.
- A social worker also may perform some of these duties at your center.

Child life services staff

- Helps children and families cope with chronic illness and time spent in the hospital.
- Provides age-appropriate support, including medical play therapy, to explain the transplant process and help children deal with their feelings.
- May help facilitate schooling options for children in the hospital.

Other staff

- May include chaplains or comfort (palliative) caregivers.

Organ procurement organization (OPO) staff

- Works with your hospital and the donor hospital during the matching and organ procurement process.

In their various roles, transplant team members are there to help you and your family. You can bring any concern to someone on your transplant team. For instance, if you need to take time off from work to care for your child, your social worker or transplant financial coordinator may know about a resource that can help.

3. Transplant evaluation

Your transplant team will order medical tests and lab work to evaluate your child for a transplant. These include blood tests, tissue-typing, organ-specific tests and a complete health history. Other tests gauge psychological readiness and social support. Results will help the team decide if your child meets the criteria to be a transplant candidate at their center. The team will also decide how to best manage your child's medical condition and when your child will be listed for an organ transplant.

The transplant team reviews all of the test results and input from team members to come up with your child's treatment plan. This includes deciding which patients to add to the national transplant waiting list. The team must inform you, in writing, about their decision to proceed to transplant (or not), and the reason for the decision. Ask questions if you need more details. If you need someone else to help, call UNOS Patient Services, at 888-894-6361.

4. The waiting list

The transplant team looks at a range of medical, surgical, psychological, developmental and social factors when listing a patient for organ transplantation. If your child is accepted as a candidate, the transplant center will register your child on the national OPTN waiting list. OPOs and your transplant center will work together to find a match. There is still a possibility that not every transplant candidate will receive an organ because deceased organs are a scarce resource.

If your child is a liver, kidney or lung transplant candidate, a living donor transplant is a possibility at some centers. If you, a family member or friend is interested in being a living donor for your child, you should contact the transplant center for information on how to start the

evaluation and testing for this process. Go to unos.org to access a wide range of resources that explain living donation.

If your child has a living donor, your child will still need to be registered on the OPTN waiting list. If you have questions about listing, please contact your transplant coordinator. In some cases, living donation may not be an option due to a patient's health status. A deceased donor transplant would be needed instead.



Keep your focus on getting your child healthy. Advocate for your child. Trust your team, but you know your child best. Do your research. Don't be afraid to ask a million questions and challenge the doctors for answers. Find support from other parents of children with similar issues.

—Amy Antonio-Claussen, liver recipient parent



You may be able to list your child at more than one transplant center. This is known as **multiple listing**. Check OPTN policy (optn.transplant.hrsa.gov) for the rules, which vary by organ. You can also ask your transplant team for more information. If you choose to do so, you will need to assure that you can easily

travel between your home and the centers. Each of the centers will need to conduct a new evaluation. You will also need to check on insurance coverage. Listing a patient at more than one center in the same area may not increase chances of transplant.

If your family needs to find a new transplant center, your new center may have to perform a transplant evaluation as well. Waiting time will carry over to the new center, but check with your new transplant team to make sure.



Organ allocation

The organ transplant system follows OPTN policies, which sets **organ allocation rules**. The national transplant community works together to create and update **OPTN policies**. You can find the OPTN policies at optn.transplant.hrsa.gov.

The UNOS computer system stores medical information about donors and candidates. It uses rules to match organs with patients on the waiting list. Rules differ for each organ. Some of the rules help children who are waiting rise higher on the list because of their disease, complications, or their weight or size. Go to the UNOS Transplant Living website (transplantliving.org) to learn more.

Pediatric priority

It may help for a child to join the waiting list **before** they turn 18, depending on which organ they need. It definitely affects kidney allocation. It is called **pediatric priority**. If a child starts dialysis before their 18th birthday but is added to the waiting list after they turn 18, they would not receive priority. Review OPTN kidney policy (optn.transplant.hrsa.gov) and check with your transplant team to see if this is an option.

Depending upon the organ a child needs and the nature of their illness, there may be other factors that could increase the chances to receive a matched organ. The OPTN defines those factors as **exceptions**. They may vary over time, in response to a child's needs. Your transplant team can advise you. See the OPTN website (optn.transplant.hrsa.gov) for a list of OPTN policies that address the needs of some transplant candidates under age 18.

The team's goal is to make sure that transplant remains the best option for a patient. There may be times when a patient is too sick for transplant. Sometimes, the transplant team may have concerns that a family cannot manage all of the care required for a successful transplant.

If the team decides that a patient is not eligible for transplant, they will explain why and will work with the family to help figure out the next steps.

5. Waiting for a match

Waiting for a transplant is not like going to the driver's license bureau and standing in line, waiting for someone to call your number. You may want to think of it as a pool of people, waiting for an organ that fits their medical profile. Doctors and nurses at your transplant center will review medical information about available organs to find a good match for your child. Sometimes, an organ may become available, but your doctor may decide to wait for a better match.



When my son was listed, we set up a checklist of everything we needed to do in order to get out of the house and on the way to the hospital.

—Dorie Neuhaus, heart recipient parent



Waiting for a match can be emotionally difficult for your child and your family. See the **Parent's Toolkit** later in this section for some suggestions on how to handle emotional concerns.

Some patients wait for a transplant for several months or years. Make sure that your child has a consistent daily schedule during this time. If your child is waiting for transplant at home, talk with your medical team and follow their suggestions about activity limits. If a child is waiting for transplant for an extended time in the hospital, talk to the child life specialist for a schedule and activities appropriate for the child's age, developmental level and psychosocial needs.

The transplant team will monitor a child's condition as they wait for an organ offer. Some children could become more ill and may need to wait in the hospital. If a child is already in the hospital, they may need to move to the **intensive care unit (ICU)** to wait.

In other cases, transplant may not be the best option for a while. The transplant team may want to wait until the patient's condition improves. If that happens, the transplant team could change the status on the waiting list from "active" to "inactive." The patient would not receive organ offers during time on inactive status.

If a patient's health continues to get worse and transplant is no longer an option, the team could decide to remove them from the list. This is a tough call, but doctors do not want to put a patient through a transplant if it would not be a success.

You have the right to know about all of these decisions. Your transplant team must inform you when they add your child to the waiting list, when they remove them and the reason they were removed. Call **UNOS Patient Services** at 888-894-6361 if you have questions.

Get ready while you wait

Waiting for transplant can make you feel like you, your child and your entire family are living life on hold. During this time you may feel that there is nothing you can do. Getting ready for transplant can help to provide a sense of control as you wait.

Plan ahead

- Keep a records binder or use a smartphone app to manage all your child's medical information, appointments and medicines.
- Use calendars to keep track of family business (bill-paying, home maintenance, etc.). Checklists can also help.



- Find out the hospital's visiting rules, figure out where to park and note details about where to find food and where you can store your bags.
- Write down your questions when you think of them so you'll have them ready the next time you meet with someone on the transplant team. Prepare to communicate your concerns openly. Take notes during meetings and appointments.
- Discuss and decide how you will handle difficult decisions in your child's care.
- Create a "go" plan and practice it with your family, so you are ready to get to the hospital when it is time for your child's transplant. Pack those bags! Make plans for care of your other children, your home and pets.
- Set aside money for travel or lodging so it will be easier to get to the hospital.
- If you will be driving to the transplant center when your child is called for transplant, plan your route to adjust for driving during the business day and rush hour versus a Sunday morning. Find alternate routes. If you are driving to the airport, make sure you have the same type of plan.
- Plan for you and your child to stay near the hospital, if asked.
- Plan where you will stay after the transplant. Most transplant centers ask that families stay in the area for a few weeks after transplant if they live an hour or more from the center. Your social worker is the best resource for convenient and affordable lodging.

Keep in touch

- Provide all of your home, work and cell phone numbers to the transplant team so they can reach you at any time, night or day.
- Gather contact information for all family and friends and keep it handy. Consider how you would like to provide updates to your circle. If using social media, be cautious about privacy concerns when sharing sensitive information. See the social media guidelines on unos.org to learn more.
- Find a primary support person or divide tasks among your group to cover family needs.
- Tell relatives, friends, clergy and others what's going on in your family's life. You may want to ask someone in your circle to do that on your behalf.
- Reach out to your transplant coordinator, social worker, psychologist or your child life specialist to help you with how you are feeling, your concerns and worries. Talk to them about what you and your family are going through as you wait for transplant.

Support groups

Many families and transplant recipients find help by staying in touch with people in the same situation. Here are some tips to find people with whom you can relate.

- Your transplant center may have online or in-person support groups; ask them for details.
- Talk to other parents that you may meet while your child is in the hospital. Those relationships can be some of the longest-lasting and helpful support you'll find. Other transplant parents may be aware of support resources that you don't know about.

- You may not find many people in your area whose experiences are similar to your own, but there are many active communities online.
- Sites like transplantbuddies.org serve as a support system for transplant recipients and their families. You can also find support group listings and events on transplantliving.org.
- Talk to organizations that advocate for organ-specific transplant issues. Some of these groups run their own support forums on social media sites like Facebook.

After you've found your way into a support system, don't be afraid to ask if anyone in that system is aware of a group that might fit your needs more closely.

6. The call (organ offer)

Your transplant team will contact you when an organ is available that is the best match for your child. Answer your phone, day or night, especially if the call is from the transplant center. You will need to get to the hospital quickly. Contact members of your support group and ask them to handle other duties while you focus on the upcoming transplant.



The 'call' is an overwhelming experience. There is absolutely nothing they can tell you that will prepare you for the emotions that take over when the call comes in.

—Dorie Neuhaus, heart recipient parent



When you arrive at the transplant center, get ready for more tests to prepare your child for surgery. At this point, you and your child may feel excited, anxious, afraid or peaceful. You may also grieve for the family who lost someone, but feel grateful that your child will receive the gift of life. Donor information is confidential and you won't receive gender, age or other details about the donor.

You may find out that final tests show that the organ is not suitable for transplant. You and your child may be disappointed to leave the hospital without a transplant. Your transplant team will use only organs that will give your child the best opportunity for a good outcome, but this kind of uncertainty can be hard to handle. Your reactions might include anxiety, grief, guilt, depression, anger and confusion, to name a few. You should lean on your transplant team to help you deal with your emotions. Your transplant coordinator, social worker, child life specialist, psychologist, chaplain and other team members can help you find strength so you can support your child and family.

7. Transplant surgery

Each transplant is unique, but the surgery generally lasts from four to nine hours. It may take even longer for patients receiving more than one organ. All patients are placed on a **breathing machine (ventilator)** for the operation, but many patients will need to stay on the breathing machine after surgery too. Your child will likely spend time in the ICU or intermediate care unit.

Each patient recovers differently. Ask your transplant team when your child can expect to eat, walk and return to normal activities after transplant.

Caring for your family and yourself

Parent toolkit

A parent is the foundation of any family. Balance the needs of your children with your own needs and be sure to take care of yourself so you can be available for them. Being in a constant state of crisis, even for a short time, can make you less able to support your family. If you spend your time worrying about the "what-ifs," it may be tougher to deal with issues happening right now.

Parenting can be a challenge with healthy children, so having a child who needs a transplant can add additional stress. Here are some points to keep in mind:

- Raising a family is a long-term project. Even though things are not how you wish them to be right now, it will be possible to find a new normal.
- Forgive yourself if you cannot be present for everyone all the time. You have a lot going on. Sometimes, you may just need a short break.
- Take a brief mental vacation when you can, even if for a few minutes at a time.

Manage your reactions

Keep tabs on your emotions. It can be challenging to manage your feelings and stay on an even keel, but it will help you focus on all of the other tasks you need to handle. You can show your children a positive example of how to handle tough situations. They can carry your example with them as they grow and develop toward greater independence.



I wish we had known earlier about getting our family involved in counseling. After the physical, the mental and emotional aspects of transplantation need just as much attention.

—Tim Harrod, heart recipient parent of twins



Get help

Each of you will have a different emotional reaction to transplant. Some parents feel guilty that their child needs an organ transplant, even more so if the cause is genetic. Others may be highly anxious, or even suffer from post-traumatic stress. You may need to get counseling during or after your child's transplant.

There are no right or wrong feelings, but there are people to help. Seeking support is healthy for the whole family. Talk to your transplant team to find out about therapy that may be available to you. Your health plan may cover counseling, even if you need it long after the transplant. Faith-based services may be another option for you.

If you are concerned about how hereditary medical issues may affect your other (or future) children, seek out genetic counseling to learn about the risks.



Getting help should also include accepting people's offers to help. Whether it's watering the plants at home, bringing you some food, playing cards with you or something else, it is important to let others in during this time and not try to carry the weight yourself.

Find balance

You may hear "transplant is not a cure." Transplant is a treatment that may provide a better quality of life. Most transplant recipients require a lifetime of medications and will need to manage a chronic condition. There may be activity limits, side effects and frequent contact with doctors and nurses. Life is a balance. Help your child learn coping skills so they can handle these realities.

Laugh

Not every family finds it easy to laugh together. Connect with your loved ones with a smile, a laugh or a good memory when you can. It can help to smooth the path to healing and make the hurdles easier to face.

Ask questions

There will be a lot of complex information coming at you. Most of us don't recall what we hear in a doctor's office. It's especially tough when you first learn about your child's illness and need for a transplant. Keep asking questions until you understand. Your transplant team will explain information that you are unsure about so that you can help your child and family.

Write questions down before doctor's appointments or rounds. If in the hospital, ask for a pen and paper, use a whiteboard, or keep notes on a phone or tablet. Sometimes it is useful to record doctors (ask first) and listen later when you can digest the information more easily.



One of the hardest things I see families struggle with is the uncertainty. When a child is sick enough to be in the situation of even talking about a heart transplant, families are in crisis mode. We do our best, I hope, to provide a lot of information about what a transplant looks like and what the future will bring, but there is no way a family could realistically either fully understand that or that we could really fully explain it.

—Dr. Jeffrey Gossett, pediatric cardiologist



It may be helpful to have a trusted person come with you to appointments in addition to your spouse or co-parent. They can serve as another set of ears to take in the information and help you process it later.

Look forward

Turn to transplant social workers, child life specialists, psychologists and psychiatrists to help you plan for life after transplant.

- Setbacks happen. Recovery can have its ups and downs. There is no timeline for when to expect grief, guilt, new concerns, new questions or old fears to pop up.
- Speak with your transplant team about when and what activities your child can pursue. See *Section 2: After the transplant*, for details.

Learn

Understanding all the new medications, terms, processes and people involved in a transplant can seem overwhelming. Learning about these things will help your child live life to the fullest. You will also be able to pass along your knowledge.

Explaining the transplant process and deceased donation to your children

Your child will probably have a lot of feelings about the upcoming surgery. Children may feel anxious or angry about so many doctors' visits, lab tests and side effects that other children do not have to face. They may show frustration with their health limits and with the need to wait for transplant.

To help explain the process and why many patients have to wait for a transplant, read *What Every Kid Needs to Know* with your young children. Go to the **UNOS store** at unos.org to access the booklet and to find other free resources for transplant patients. Child life services can point you to other resources or activities for younger children.

You may get questions about where organs come from. One way to describe transplantation to younger children is to explain that a transplant is like changing the batteries in a favorite toy. Most children will have seen a parent do that or even helped their parents "replace a part" that no longer works.



Reinforce the idea that receiving an organ, either from a deceased or a living donor, is a special gift. Older children and teens may express a concern that “someone had to die for me to get an organ” through deceased donation. You can explain the events that led to the donor’s death would have happened, whether or not your child needed an organ.

Siblings may feel hurt or sad that Mom and Dad can’t spend as much time with them. Each person shows feelings in different ways, depending on their age and personality. Sometimes it’s hard for siblings to express negative feelings. They may hurt or ignore each other’s feelings without meaning to do so. One or more family members may need time to process their emotions.

As a parent, you may need extra time as well.

Talk with your children. Ask them questions. Engage in active listening, and be present in the moment. Be open to all questions and let your children know it is OK for them to have lots of different feelings about what’s going on, including feelings they can’t explain.

Focus on what they say and how they say it. If you see changes in the way your children act or behave with each other, you may want to reach out for support from a social worker, psychologist or counselor.

Financing your child's transplant

Thinking about paying for a transplant and all of the costs involved can raise many questions and concerns for your family. Your financial coordinator or social worker can help you create a financial plan.

UNOS' patient website, transplantliving.org, is a great resource. The site has details about transplant expenses, funding sources and a list of questions.

If living organ donation is in your child's future, there are programs to help pay for the living organ donor's expenses. Your transplant team can tell you more about those groups. You can also get more information on transplantliving.org.

What follows are some common options to pay for transplant expenses. Most families use more than one funding source to pay for expenses not covered by health insurance. Some of these sources include savings, other private funds and fundraising.

Private health insurance

If you have health insurance, you may want to start by finding out what your plan covers. Then you can begin to explore other funding sources. Terms and extent of coverage vary widely and may change from year to year. Read your policy carefully each year and ask your health plan representative what types of costs are covered before, during and after the transplant. Find out if you have to use network providers and when you need to get authorization. If you have questions, call the insurance company directly or contact the human resources department at work. The health plan may assign a case manager to walk through the process with you.

You may have other coverage that will pay for costs or you may have to cover deductibles and other expenses.

Staying on top of medical bills

Your financial plan needs to cover costs before, during and after the transplant. Expect a high volume of bills and benefit statements. For your peace of mind, set up a process ahead of time to make sure all of your child's transplant-related bills are covered. Mistakes happen. If you think something is wrong, address it in a timely manner to help reduce stress.

Government programs

Medicare

Medicare ([medicare.gov](https://www.medicare.gov)) is a federal health insurance program available to people:

- Age 65 or older and those under age 65 with certain disabilities, or
- Any age with "end-stage" renal (kidney) disease, or *ESRD*.

Medicare, like most private health plans, does not pay 100 percent of your costs. You must pay deductibles and other expenses.

To receive full Medicare benefits for a transplant, you must go to a Medicare-approved transplant center. Contact your local Social Security office or go online to find out more.

Medicaid and CHIP

Your child may be eligible for Medicaid ([medicaid.gov](https://www.medicicaid.gov)) or Children's Health Insurance Program (CHIP). Each state runs its own program, following federal rules. Check with your social worker or financial coordinator. If you are eligible for financial assistance, provide a copy of your federal tax form or Social Security award letter to the transplant team.

Fundraising

Even if you have medical coverage, you may need help paying for other transplant-related costs and living expenses. Local, regional and national organizations provide patient assistance and sometimes grants. They can advise you about how to raise funds to help pay for expenses that are not covered or living expenses while you are away from home. Check with your financial coordinator, social worker or insurance case worker to be sure fundraising does not disqualify you from other assistance programs or if those funds have to be included in your annual income for tax purposes.

The following organizations can help with fundraising for transplant:

- The *Children's Organ Transplant Association (COTA; cota.org)* Contributions are tax deductible for donors and recipients of COTA funds for their benefit
- *National Foundation for Transplants (transplants.org)*
- *Help Hope Live (helphopelive.org)*

You may want to look at patient advocacy organizations that cover your child's diagnosis. They often have funding available to help families who are waiting for transplant.

Some people prefer to fundraise using a crowd funding site on the internet. Although these sites are often successful, keep in mind that funds raised through these sites can be subject to fees and taxes, and may also affect eligibility for state programs. Your transplant financial coordinator or case manager may be able to help answer your questions about this type of funding.

Taking time off work

Parents who take time off work to care for a child after transplant should talk to a human resources representative at their workplace. Parents should be aware of the *Family and Medical Leave Act (FMLA; dol.gov)*, that will help retain their job while away from work.

Although your family's transplant journey can be difficult and stressful, your transplant team and many other people can help you through it.

Section 2

After the transplant



For kids of all ages

Follow-up care and labs

Your child will have routine check-ups, labs, and procedures to be sure that they are healthy and that the transplanted organ is working well. Most patients are monitored very closely in the first few weeks after transplant. Over time, as your child recuperates and the transplanted organ is working well, this monitoring decreases. For many patients after a couple of years, the transplant team requests that labs be obtained every month or so and that your child has a clinic visit every six to 12 months.



I've lived more healthy years now due to my transplant than years sick when I was a child. Years that I wouldn't have if a donor family from Tennessee hadn't donated their son's organs. My outcome may not be typical, but it's possible.

—Kim Uccellini, pediatric kidney recipient



Sometimes, the transplanted organ needs to be checked more closely, and a biopsy is performed. Most patients can have a biopsy done as an outpatient procedure, but some patients spend one night in the hospital.

Imaging studies such as CT scans and MRIs may also be needed more frequently.

After having a transplant, some children may become a little anxious, withdrawn or depressed, especially if they have been in the hospital for a long time. Other children have difficulty focusing or interacting with others. If you are concerned about your child's mood after transplant, please discuss your concerns with your child life specialist, social worker, psychologist or transplant coordinator. They can help you find supportive services in your area.

Medical ID tag

You may think about getting your child a medical ID tag. They commonly come as bracelets or necklaces. Bracelets may be a better option for younger children. The tag should contain the child's name, diagnosis (including what organ the child received), and contact information for you or your transplant center. Newer smartphones may have a medical ID feature. You will need to update the information if anything changes.

Medications

Most patients are prescribed one to three medications to suppress the immune system so that the body will not reject the transplanted organ. After transplant, you and your child will learn much more about these medications. Transplant centers usually provide a discharge manual and education to explain why these medications are prescribed, how they work and what side effects a patient may have. Transplantliving.org is another resource.

Medications may be needed to support the transplanted organ. After a heart transplant, some patients may need medications to stabilize the heart's rhythm or to help the kidneys control the amount of acid in the bloodstream.

Other medications prevent or treat infections or help with kidney function. Most patients take an antacid to prevent stomach irritation. Many patients need electrolyte supplements to help keep blood components stable and in normal ranges. These usually include medications to help with levels of potassium, magnesium, sodium bicarb and iron.

If your child takes medications for conditions unrelated to transplant, your transplant team will help coordinate with other providers.

Some things to keep in mind

- All medications given to your child should be cleared by the transplant team. Provide transplant team contact numbers to your child's other doctors and health care professionals so they can work together to prevent drug interactions and side effects.
- Tell the transplant team about over-the-counter pain relievers, teething gel and herbal supplements or home remedies you give your child.
- Make sure your child takes the correct dosage in the prescribed time frame.
- Find out how soon you can request refills. Mark these dates so that you never run out.
- If your child throws up the medication, ask your team when you can give another dose, and how much. Be sure to note times and dosage amounts.

- Your child should avoid grapefruits, pomelos, pomegranate or juices and soft drinks that contain those fruits. They can interfere with immunosuppression and potentially cause damaging blood pressure levels.
- Some medications increase the risk of skin cancer. Apply sunscreen even on mildly sunny days.
- Ask the pharmacist about medication discount cards.

It is common for medication doses to change over time. Your child may gain or lose weight, need a higher or lower level of immunosuppression or your child's electrolytes may be out of balance. Your transplant coordinator will contact you with any medication changes and answer your questions. Never change doses on any medications without talking to your transplant team.

Preventing organ rejection

Rejection is the body's defense system to get rid of anything seen as "not self" or foreign to your body. Usually this is a cold virus or the community flu but in a child who has had a transplant, the immune system may react against the transplanted organ. Immunosuppressants suppress the normal immune system so that the transplanted organ is not rejected.



What are the common signs of rejection?

Rejection can be sudden (acute), or may occur over time (chronic). You may not be the first to notice signs of rejection in your child. Your transplant team will tell you what to look out for. If you are worried or notice a change, talk to your child's doctor.

How can I help reduce my child's risk of rejection?

- Give your child the correct dose of prescribed medications on-time each day. This is the most important thing you can do to reduce the risk of rejection.
- Exact timing of dosing can be important for some medications, so set up a regular, seven day-a-week routine.
- Know the signs and symptoms of rejection for your child and contact your transplant center if you are concerned your child may have any of these symptoms.
- Contact your transplant coordinator with any changes in your child's health, particularly in the first year after transplant.
- Get your child's labs drawn as requested by your transplant coordinator.
- Make sure your child attends all required appointments for clinic, tests and procedures.
- Check with your transplant coordinator before giving any medications prescribed by another physician, or if you would like to use over-the-counter medications or herbal supplements. Rejection episodes may occur as your child's immune system adjusts to the new organ. While the risk of rejecting an organ can decrease as time goes on, it never goes away. Your transplant team can provide more details.

Vaccines and staying healthy

Children are exposed to common illnesses at school and elsewhere. These range from the common cold and flu to measles, chicken pox or whooping cough. Immunosuppressants make it difficult to fight disease

and make transplant recipients more prone to infections. Ask your transplant team and your child's doctor about what they suggest for a vaccine schedule. You may want to use the **Centers for Disease Control and Prevention (CDC) schedule for transplant recipients** (vaccines.gov) as a guide.



What helped me the most was having a fellow transplant mom tell me about her medicine organization process. It made things so much easier to have a true system when we got home.

—Carie Semenko, heart recipient parent



Some of the required immunizations that are given to children are “live” vaccines, which work by giving the patient a very small amount of the actual virus so the immune system learns to fight that virus. Most transplant centers recommend that transplant recipients **do not** receive live vaccines after transplant. They also recommend that patients being listed for transplant get **any** live vaccines **before** transplant whenever possible.

The pediatrician may use a schedule that moves up the dates of the immunizations to be sure they are given before transplant. Some transplant centers advise that family members not receive live vaccines. Talk to your transplant team about what they recommend if other family members need to have live vaccines.



Your child receives added protection if other children, family, friends and others they come in contact with are up-to-date on their vaccines and flu shots. This is called **herd immunity**.

Ask your child's school nurse to inform you if any students have a community illness that is controlled by vaccines, such as chicken pox. If your child is not immunized and has been in close contact with that student, there is a risk of getting chicken pox. Call your transplant coordinator for advice on what to do.

Hygiene

Your child's immune system is compromised in order to prevent organ rejection, so it is very important to avoid exposure to sources of infection. Good hygiene is part of this, as well as decreasing exposure by avoiding others who are ill, being careful in public places, where germs may be present on doorknobs or countertops. Carry hand sanitizer in case soap and water are not available.

Travel

- If you plan to travel outside the country, check the Centers for Disease Control and prevention (CDC) website (cdc.gov) for information about significant health problems at your destination.
- If flying, it's best to pull medications out of your bags and identify it to TSA. It will always get an extra screening. So plan for extra time.
- If traveling for a biopsy, try to limit movement in your child's surgery site (groin, chest, etc.). Very young children should be in a stroller. A wheel chair may be helpful.
- If you must travel for care, insurance or your care fund may cover the cost of an extra seat for your infant or toddler.
- For long plane trips, keep your child well hydrated. Drinking water during the flight and avoiding caffeine can help reduce jet lag symptoms. This is good advice for you, too.
- Ask your doctor if you can skip magnesium or diuretics that might make your child urinate more frequently.



Travel for vacation

- Ask your center for a travel packet. It contains information about your child for emergency responders and hospital staff.
- Ask transplant team members to help you locate the nearest transplant treatment centers in your travel area.
- Check with your transplant coordinator before leaving the country.
- Take sunscreen with an SPF of 30 or greater if you travel to an area where your child will be exposed to the sun for long periods of time.

For any travel

- Bring original prescription bottles with labels. You may want to ask your transplant coordinator for a letter listing all medications and medical care that may be needed.
- Bring special formulas, nutritional and supplies with you if they may not be available at your destination. Contact airlines in advance to request luggage allowances for these products, if needed.
- Take an extra supply of medicines with you in case you are delayed.
- Keep medicines with you at all times. Never put them in checked luggage.
- Think about time changes and how that might affect when to give medications.
- Talk to the pharmacist about the safest way to transport medications that need to be refrigerated.

Contacting the donor family

When you and your family are ready, you may want to express your gratitude to the donor family by writing a letter. This gesture can be a source of solace to donor families, by knowing that their loved one's death helped others live. Check with your transplant team or your local organ procurement organization (OPO) for guidance.

General guidelines:

- Timing for this letter will vary by transplant center or OPO.
- Do not include any personal or identifying information. Use first names only.
- Share a story about how your child is doing. Tell the donor family about how your child's health has improved with their generous donation of the gift of life.
- Most centers ask you to include a photo of your child.
- Never contact the donor family on your own, through social media or any other way. Always work with your OPO and transplant center to contact a donor family, so your letter arrives at an appropriate time as they grieve.

Caring for your child through the ages

Newborns to age 3

Recovery after transplant

Although many children recover well after transplant surgery, some children need support during their recovery. This depends on how sick the child was before surgery, what type of transplant they had, complications they may have experienced and how long they were in intensive care and the hospital. Being away from family, friends, school and their normal routine can also affect how children recover.

Here are some examples of challenges children may have after transplant. Ask your transplant team about therapy or services to address your child's needs.

- A young child may need to adjust to eating after transplant. It may help to stick to a few basic food tastes and textures to start. Children who have trouble eating or drinking, or with strict food limits, might need a feeding tube. A dietitian can help with a feeding schedule, if needed.
- Some children need help regaining developmental milestones after transplant. For example, a child who was toilet-trained, may not want to use the potty. Talk to your transplant team if you have questions or concerns.
- Infants and children who had a heart or lung transplant will need to be on chest ("sternal") precautions for six weeks or more. This could cause delays in learning how to roll and other milestones.
- Physical and occupational therapy can help children who experience muscle loss or atrophy after transplant. This can occur when a child is on a breathing tube or heavily sedated for a long time.
- A child's growth may be a concern after transplant. Discuss issues and options with your doctor and transplant team.

Federal programs

For children who need additional help after transplant, services may be available on the federal, state or local level. Many of these programs have specific guidelines that may differ from one program to another. Ask your transplant social worker or coordinator for details.



After transplant, your child is still a child. They will still have tantrums. They will want to play with mud. Just like any kid. That's why they got the transplant – to be a kid.

—Joseph Hillenburg, heart recipient parent



Some children with medical conditions may develop more slowly than their peers. Early Intervention (EI) Services (an Individuals with Disabilities Education Act [IDEA] program) provide education and support to help eligible newborns through age 2, reduce the effects of delayed development. Talk to your care team about EI if you feel it will benefit your child.

Your child will be assigned a service coordinator and therapy team to assess them. If the team decides your child qualifies for EI, they will write an individual family service plan (IFSP). They will include you in the process and will work with you to best meet your family's needs.

The earlier EI begins, the better chance a child has to succeed and catch up.

School-aged children

There are no-cost public school programs to help your child have a successful and enjoyable school experience. They can help a child catch up on missed school work, manage fatigue or handle other issues that may impact learning before or after transplant. The following are some of the programs.

Individualized health plan

An individualized health plan (IHP) can help with your child's medical needs while at school. They may include details about blood pressure checks, taking medicine, use of bathroom and how to handle emergencies. Talk to your child's school nurse to help you get started.

Section 504 plan

Section 504 of the Rehabilitation Act of 1973 allows you, together with your child's school, to lay out a written plan that explains how the school will meet the individual needs of your child. A 504 plan makes sure a child who has a disability as defined by law and goes to public school receives accommodations to help them be successful, participate safely and have the same access to education as other students. Accommodations could range from home tutoring to extra time to complete homework. The plan helps eliminate misunderstandings. If you are interested in exploring a 504 plan, contact your child's teacher or school counselor.

Individualized education plan

An individualized education plan (IEP) provides specialized instruction and services to help children with a disability as defined by the law. It is an agreement between parents and a child's school to address the child's unique learning issues and meet their educational goals. If you feel that your child needs more help at school, talk to their teacher about an IEP.



It's hard enough being a teenager. Adding a medication to the list of things to worry about makes it that much harder. Take your medicine. That medication will allow you to embrace the many highs that life has in store for you.

—Bill Coon, pediatric heart and adult heart/kidney recipient



Teens: risky behaviors

Kids face unique challenges as they get older. When your child enters the teen years, things change. Your child may pull away from you and participate in riskier behaviors. This is part of normal teen development, but it is important to stay engaged to help keep your child safe.

Adherence

Transplant recipients need to stick to a treatment plan to stay healthy. Your transplant team may refer to this as **adherence**. It includes scheduling appointments, completing lab work and medical tests, and managing medications. Younger children depend on parents and caring adults to handle scheduling conflicts, health concerns and problems with medications. As your child gets older, adherence can become a challenge. Research shows an increased risk of rejection during teen years, and lack of adherence can be a factor¹.

Seeking independence is a normal developmental milestone for teens. They naturally start to spend more time with friends and strive to fit in. Not all teens share with their friends that they have had a transplant. This may make it tougher for them to take medications on time and can lead to non-adherence. Encourage your child to share this information with close friends.

Find ways to help your teen remember to take medications. It could be as simple as setting a watch or clock, or finding a good smartphone app. You can also help set up a pillbox so that all your child has to do is take out the pills needed during the day, without having to think too much about it.

You can also ask your teen what they think will work for them. Some older teens may want to take medications a little later in the morning so they can sleep a little later. They may need to take medicine at school instead of home. There may be side effects that your child does not like. Help your child discuss this with their doctor to see if they can make a change. Teens who own their care are more likely to adhere to it.

If your child begins to slide toward non-adherence, stay on top of the situation. You may need to step in and supervise for a time. A social worker, psychologist, or mental health specialist can help. Talk to the parents of other transplant recipients of the same age. Your child may benefit from meeting transplant peers. They will understand the struggles your teen faces. Some transplant centers host teen events or mentoring programs where kids can meet, exchange ideas and get advice.

Non-adherence can lead to devastating results, including organ failure. It could also affect the possibility of getting another transplant. If you have concerns, talk to your child right away and reach out to your transplant team for support.

Emotional Turbulence

Adolescence is already noted to be an emotionally charged period in any child's life, but add in life-threatening illness or disease and the result can be overwhelming. Your child may experience feelings of anger or jealousy as they question "Why me?" It is important that you keep an open line of communication with your child as they express their feelings of anger, frailty or injustice.

Your child may also feel isolated or depressed during hospital stays or while they are home recovering from the transplant. Be sure to work with your transplant team if emotional concerns arise to make sure you are able to access counseling or psychiatric support to help your child work through these feelings. Their emotional status is vital to their transplant recovery and follow-up treatment plan.

Your child can lead a very fulfilling and relatively normal life. Don't let a transplant restrict your or your child's dreams.

—Megan McKinley, pediatric heart and adult heart/kidney recipient

Your child may feel anxious about their future and what their life might be like after the transplant. Other family members may share the same feelings of anxiety and stress that need to be addressed as well. Working together is the best way to stay strong through turbulent times.

Alcohol and drugs

Peer pressure is powerful and transplant recipients are just like other teens when it comes to trying drugs and alcohol. They may know the risks of these behaviors, but like many people, they believe it will not happen to them. This is normal.

It's hard to strike a balance between giving a teen some space while making sure that you watch out for their health and safety. Don't be afraid to discuss this subject openly with your child. Suggest ways to explain to their peers that they can't drink or do drugs because of the medications they need to take. You can also encourage them to join clubs and activities that do not allow drugs and alcohol. Turn to your transplant team for other suggestions.

Still, many teens will choose these activities anyway. Leave the door open for honest discussions with your teen about what's going on in their life. It will help them to know they can tell you about drinking or drug use, and that you will work with them to figure out what happens next.

Some transplant centers tell adult (over age 21) transplant recipients that no alcohol is allowed at all. Other centers may allow a drink every now and then. Alcohol impairs judgment, which could lead to other risky behaviors or forgetting to take medications.

Transplant centers frown on any form of non-prescribed drug use. Your child needs to learn about the risks of infection and interactions with illegal drugs, or marijuana, which may be legal in your state. Most drugs are not pure, which also adds another layer of risk. Intravenous (IV) drug abuse exposes your child to many communicable diseases that are dangerous for a transplant recipient. If your child ever needs another transplant, active use of illegal drugs could affect future candidacy. Keep talking to your child about these issues through the years.

Sexuality

Sexual activity is a part of life for most adults. Your teen is becoming a young adult and will eventually move in this direction. All parents struggle with this as their child matures. Naturally, you want to reinforce your expectations, but it is even more important to prepare for reality.

Sexual activity includes genital, anal or oral contact. Many teenagers do not consider it "sex" if it is not intercourse. You and your teen need to know that all sexual encounters can be risky. As your child approaches puberty, your transplant team may start to discuss these issues with your child. Understanding the risks is key to preventing them.

All sexually active teens risk being exposed to sexually transmitted diseases, but an immunosuppressed child is at a greater risk. Because of this, open communication between you, your child and their transplant center is imperative.

Vaccines and condoms will help protect your child against many forms of sexually transmitted diseases. Be prepared to discuss these methods with your child's transplant team.



Transplant team members may ask to speak with your child without you in the room. Your child may request privacy as well. This allows a child to bring up parts of care that they may not want to discuss in front of you. If the health-care provider starts this process in the young teen-aged years, it becomes a normal part of the clinic visit. It will help your child trust the health-care system and teach them that they can speak freely with their doctors.

Your transplant center may be able to refer your child to a clinic or program that specializes in sexual health. These clinics can counsel children, educate them about risks and prevention, and offer sexual health screening and birth control. Immunosuppressed recipients who are sexually active may need more frequent follow-up.

Teenage girls should know the risks associated with pregnancy. Some centers may advise certain young female recipients that it is not safe to become pregnant. A teen could also be on medication that

could harm a fetus. In either case, you should talk to the transplant team about effective and safe birth control, based on your belief system. Barrier methods like condoms or spermicides are generally not considered enough on their own. Your transplant center can advise you on the safest method for your child, including birth control pills, IUDs or something else. Some types of immunosuppressants interfere with the effectiveness of birth control pills.

Some centers recommend birth control once a child reaches puberty, even if they are not sexually active. You, your child and your transplant center will decide together what is best. The main goal of these discussions and suggestions is to prevent disease and pregnancy.

Young Adults: Independence and transition

Advanced preparation that takes years

In your child's early teenage years, your transplant center will begin to emphasize independence. Since your children will not always live with you, it's important that they learn to take care of themselves. Many children are ready to learn about self-care as young as 12 years old, while other children need more time.

Whenever the process starts, it should be gradual and involve both the parents and the transplant center.



Empower your child or teen to be independent and learn to take care of themselves. You might not always be around to do things for them or ensure they make smart decisions. I attribute my success to my parents making me be accountable and responsible and not rely on them.

—Kim Uccellini, pediatric kidney recipient



You need to balance letting your child learn on their own and stepping in when needed. Allow plenty of time to prepare yourself for emotional struggles that go along with change.

Some transplant centers have tools that predict how prepared a child is to take care of themselves. These tools help parents and the transplant team know the areas where they are needed most. You can use these tools to mark your child's progress. As children age, they can learn to be responsible for their own care in the following areas:

Medications

They should know the names of medications, doses and what they are for. They should recognize the pill even when it's not in the bottle and know when to take it. A perfect time to teach young children about medication names and doses is when you fill their pill box. You can start teaching early if you believe your child is ready, but you should certainly begin by the pre-teen or early teen years. A young teen could begin filling their own pill box while you watch.

Older teens should keep track of medication refill dates on a calendar or on their smartphone. Teach them to call the pharmacy or contact the transplant center before prescriptions run out. Make sure they know who to call if they have a medication question or problem.

Children (adolescents in particular) may be unhappy with some of the side effects of their medicine, but these medications keep them alive. If side effects happen, both of you should talk with the doctor about other options.

Insurance

Your teen should know what type of insurance they have and carry a card. As your child gets older, explain how the health plan works and make sure they know who to call with questions. If they need a specialist, they should know who to call to get a referral.

Communicating with the transplant team

Your child should be comfortable talking with the transplant team. Encourage teens to make their own clinic appointments, and to ask and answer questions during visits. As time goes on, your transplant center will talk more with your child and ask them more questions directly. Although it can be difficult for you to remain silent, it's important for your child to learn this skill and know that you trust them to handle it. Sometimes the transplant team will meet separately with your teen during part of the appointment. This will help them gain confidence. Encourage them to write down questions ahead of time, so they remember them the day of clinic.

Turning 18, moving out or going away to school

Once your child turns 18, they legally become an adult. From now on, if members of the transplant team want to talk with you about your child's health, they need their permission. Transplant team members may even ask your child to sign a paper saying that they permit you to speak to the medical team on your child's behalf. Your child will need to sign all consents and medical documents.

If your child has cognitive delays and is unable or unwilling to make their own medical decisions, you need a legal document stating that you can make decisions for them. The document will become part of your child's medical record. Discuss this with your child before they turn 18. Your social worker can help you with the details.

Just because your child is legally an adult does not always mean they are ready for total independence. Your child will continue to need your guidance and care. Since children mature at different rates, you are in the best position to know how much support your child still needs.

It is especially important that children learn to take care of themselves before leaving home or going away to college. Giving them gradual independence during the early teen years makes the transition less stressful.

If your child's college is not near the primary transplant center, the team may suggest a local center that could follow them during the school year. It would be helpful for your child to establish a relationship with this center before they get sick. They should also find a local pharmacy.



Talk with your child, the transplant team and Student Services about any special needs they may have as a transplant recipient.

Moving to an adult transplant center

Eventually your child will need to transfer to an adult center. The exact age will be different for each young adult. Some transplant centers have formal transition programs, others are informal. The pediatric center will transfer medical records and write a medical summary for the new center. In most cases, coordinators from each program will also talk to one another.

If your pediatric center uses a developmental readiness tool, they will likely use this as a guide to prepare you and to know when the timing is right.

Both children and parents may be anxious during this time. Transitioning to adult care means that the transplant team believes your child is ready to tackle medical issues as an adult. The proper preparation will build independence and help your child succeed during the transition.



Just like any child they will always need your support. But treat them as though they are no different than any other kid. Their transplant does not define them. Their life and identity is whatever they want it to be.

—Bill Coon, pediatric heart and adult heart/kidney recipient



Adult centers tend to be larger and have more patients and more providers. This can overwhelm a young adult who may be used to a smaller team. Be sure to work with your child before the transition to get answers to their questions. Would they rather have fewer providers at first? Do they want you to go with them to appointments?

You need to know that that adult centers will expect your child to make their appointments and remember to get lab work done. They will be less likely to remind or coddle your child. They will likely give medical information directly to your young adult and expect them to follow up. This is why it's critical for a young adult be as independent as possible before the transition takes place. They need to know how to navigate the medical system, and they should be willing and able to speak up for themselves.

No matter the age, your child will still need family support. Your child may ask you to attend certain appointments.

Transitions can be stressful for you and your child. Studies show that young adults are more likely to experience organ rejection during this time, especially if they are not well prepared for the change². You can lower the risk by getting involved and developing a plan with your child. And know that transition doesn't stop once your child transfers to an adult center. The transplant team can work with your child to make this transition as smooth as possible.

Final thoughts

Put the health and well-being of yourself, your child and your family first. Managing end-stage organ disease can be a long, stressful and challenging situation for any family to endure physically, emotionally and financially. No one is to blame. Throughout adversity, a unified family provides the best opportunity for a successful transplant outcome and the optimal growth and development of your child.

An organ transplant provides your child with the opportunity to have a second chance at life with a healthy organ, if they follow guidelines for care. Many people will work with you and your child to achieve this goal.

1 Adherence and medical outcomes in pediatric liver transplant recipients who transition to adult services. Annunziato, et al. Peds tx 2007.

2 Non-compliance and transfer from pediatric to adult transplant unit. Watson et al. Peds Neph 2000.

Acknowledgements

This guide was a collaborative effort. We are deeply grateful to the following who contributed their insights, expertise, time and attention.

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People always remark to us about how strong transplant parents are. That is not how we see it. We are just ordinary people under extraordinary pressure.

—Joseph Hillenburg, heart recipient parent

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