

Pediatric Liver Transplant Education Manual

To read the information that is hyperlinked (underlined in this manual), scan the QR code to open the liver transplant information on [MyHealth.Alberta.ca](https://myhealth.alberta.ca)



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Who is this guide for?

This guide is for children and teens (under 18 years old) who need a liver transplant.

This may be a sudden and scary event for you and your family, or it may be something that you have been expecting for some time. If you have any questions about your liver transplant, talk with your primary healthcare providers or the liver transplant team.

Parents, guardians, and support people may also find this guide helpful.

You can also learn more about liver transplants at [MyHealth.Alberta.ca](https://myhealth.alberta.ca).

If you have any questions about your liver transplant, talk with your primary healthcare providers or the liver transplant team.



Brennen's Story

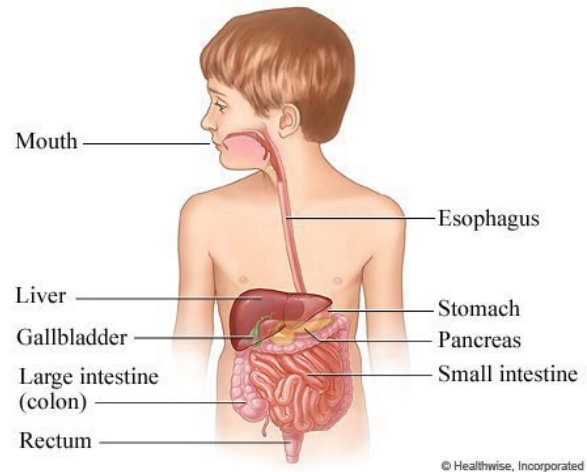
Meet Brennen. Brennen was diagnosed with biliary atresia. This happens when the bile ducts are blocked and cannot send bile from the liver to the small intestine. After trying all other medical treatments, it was determined that a liver transplant was needed. Throughout this education manual, you will read stories about Brennen and his family's transplant journey.

About liver transplants

What does the liver do?

The liver does many things. It:

- stores fats, sugars, iron, and vitamins
- makes proteins
- helps to absorb food
- breaks down fats
- changes food into nutrients
- controls your blood sugar
- filters your blood to remove substances that can be harmful to your body



With a transplant, you are trading a sick organ for a healthy one, with the hope of living longer and having a better quality of life. A transplant is a very precious gift. You will need to look after your transplant carefully for the rest of your life. Your transplant team will help you along the way.

Who can get a liver transplant?

A liver transplant may be considered as a treatment option for people with certain types of liver disease and end-stage liver disease. End-stage means that your liver may no longer be able to keep you alive and there are no more treatments to help your sick liver. There are many different causes of end-stage liver disease.

Who can donate a liver or part of a liver?

Your new liver can come from a deceased donor (someone who has died) or from a living donor (a living person who donates part of their liver).

Liver transplants are limited by the number of donors available. There are not enough deceased donors for everyone. A living liver donation may be an option for you. Learn more about [living liver donation \(video\)](#).

If someone is interested in being a living liver donor for you, have them call the [living donor program in Edmonton](#).



Brennen's Story

"For us, the most important thing that we can tell families of children who need a transplant is to never give up hope. Children are incredibly resilient and can often handle all the stress and emotion of a transplant better than the parents, at least our son did. We do not mean to say it is easy. This has, by far, been the scariest thing that we have ever been through but we just want you to know things really do get better and you can get back to a normal family life a lot sooner than you would have ever imagined."

Is a liver transplant right for me?

A liver transplant is not suitable for everyone. With a transplant, you are exchanging sick organs for healthy ones, with the hope of living longer and having a better quality of life.

It is important to know that getting a transplant involves a **lifetime commitment** to medical treatment, like taking many medicines every day, going to clinic appointments, and doing regular bloodwork and other tests.

A transplant is offered only when you have liver disease that is severe enough to need a transplant and all other treatment options have been tried. Your body must also be strong enough to tolerate the surgery and recovery.

In some cases, a liver transplant may not be in your best interest and the transplant team will discuss this with you.



If you smoke, vape, or use drugs or alcohol

If you smoke or vape any substance including tobacco or cannabis, you will need to stop before you are able to go onto the waitlist for a liver transplant. Smoking and vaping increase the chance of problems after surgery. It is recommended to avoid these substances for your whole life.

Anyone with a history of drug or alcohol use will need to be assessed by an addictions counselling team. Support is available. Your transplant team can help connect you to counselling and other services. If you do not use the counselling and follow-up services for substance use that the transplant program recommends, you will not be eligible for a transplant. You may need to do random alcohol or drug tests while you are on the transplant waitlist and after your transplant.

Should I have a support person?

You must have a parent or guardian to support you throughout all phases of your transplant journey: evaluation, waitlist, surgery, recovery, and follow-up.

It's also good for your family to have other support people to help you and your parent or guardian when needed.

If you live outside of the Edmonton area, you and your parent or guardian should be ready to stay in Edmonton for 3 months after your transplant.

You must have a parent or guardian to support you throughout all phases of your transplant journey.

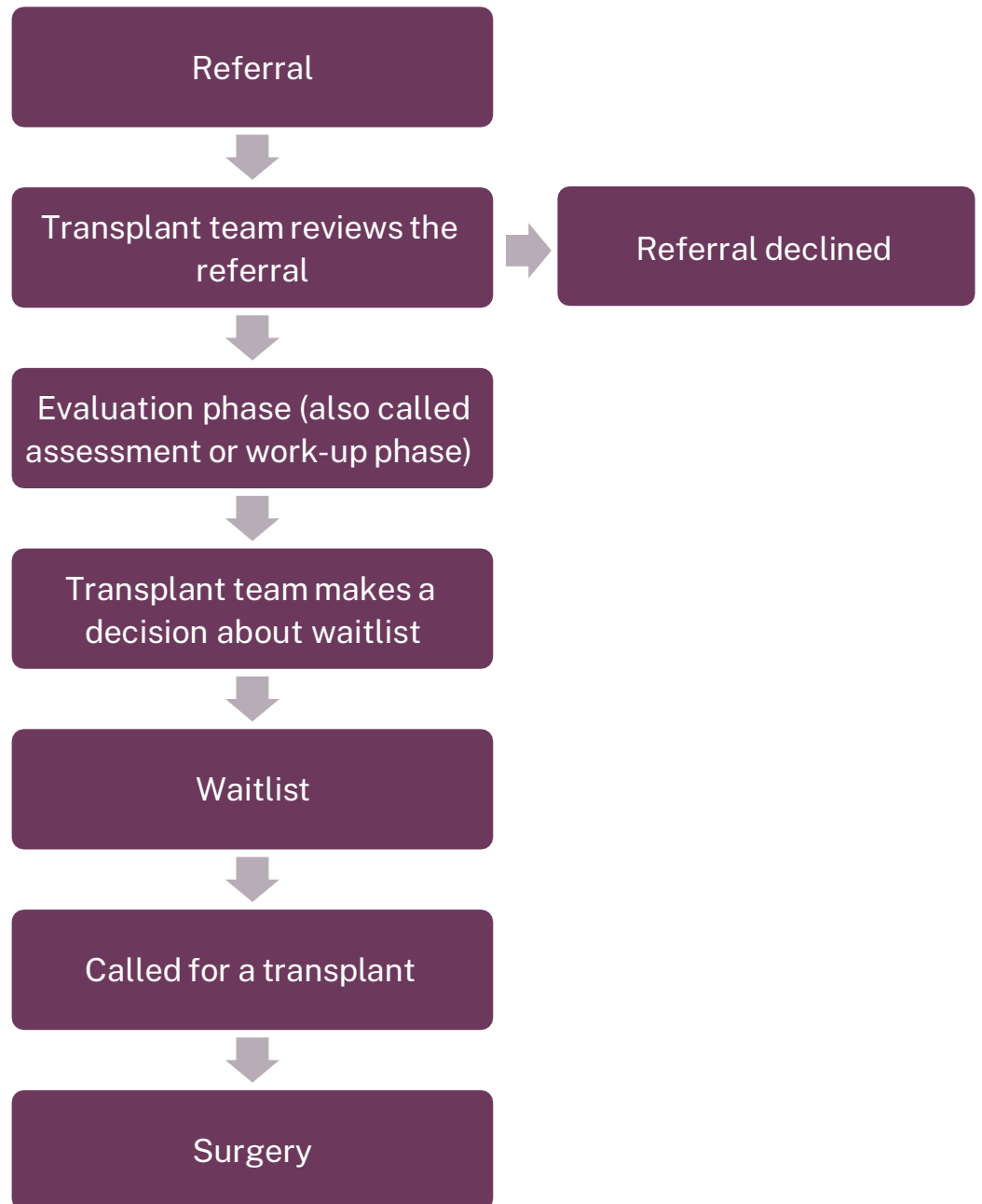
Your parent or guardian and your support people will need to:

- give their names and phone numbers to the liver transplant team
- be present for any teaching sessions (before and after transplant)
- encourage you
- listen to your concerns
- help you with taking your medicines
- go to appointments with you
- be there to help you during your recovery

Your parents or guardians will be encouraged to be with you and participate in your care to help with your recovery. Visiting hours for parents and guardians are 24 hours a day. One parent or guardian can sleep at your bedside.

Transplant process: Referral, evaluation, waitlist, and surgery

Overview



Referral

How do I get referred to the Liver Transplant Program?

A liver specialist (hepatologist or gastroenterologist) can refer you to the Liver Transplant Program.

What will happen after my referral has been reviewed?

The transplant team will look over the information in your referral. Once they have reviewed it, a member of the team will contact you to talk about what happens next.

You will either move on to the evaluation phase of the process, or your referral will be declined. Every case and experience is different.

Evaluation

What happens in the liver transplant evaluation phase?

The evaluation phase, also called the work-up or assessment phase, helps the transplant team decide if a transplant is the best option for you.

Depending on your current health situation, you may have to stay at the hospital for a short period of time to have your evaluation done. If you live outside of Edmonton, the transplant team can help you and your parent or guardian find a place to stay near the hospital.

You will be assigned a liver transplant coordinator who will let you know about what happens next.

During your evaluation, you will:

- have many tests, like x-rays, ultrasounds, CT scan of the belly (abdomen), MRI of the head, heart tests, and blood and urine tests
- have a meeting with one of the transplant surgeons
- meet with other healthcare providers and members of the transplant team like transplant coordinators, doctors, surgeons, psychologists, pharmacists, dietitians, occupational therapists, physiotherapists, child life specialists, social workers, anesthesiologists, and psychiatrists
- have support from the Child Life team with tests and procedures if needed

You are not on the transplant waitlist when you finish your appointments. The transplant team needs to get all your information and meet and discuss your case first. Your transplant team will let you know if a liver transplant is right for you.

During the evaluation phase:

- Make sure your immunizations are up to date. Some immunizations may need to happen earlier than usual before a transplant. Your transplant coordinator will review which immunizations you need during your evaluation.
- Make an appointment to see your dentist. They will check for any infections. Get your dental work done before your transplant.



For parents and guardians: Dental work

Try to have any dental work completed in your home province before your transplant. There is a cost to have dental work completed. It is a good idea to have dental coverage.

What else do I need to do during the evaluation phase?

Your case will be reviewed by the entire transplant team after they have received and discussed all your evaluation information. If they decide a transplant is your best treatment option, and you agree, you will be placed on the transplant waitlist. Learn more about being on the [transplant waitlist \(video\)](#).

If transplant is not an option for you at this time, the transplant team will talk with you about the reason why and about your follow-up care.

The waiting time for any organ can vary from hours to years. How long you wait on the waitlist depends on factors like your blood type, body size, blood test results, and how sick you are. It does not necessarily depend on how long you have been waiting.

Waitlist

What can I expect while on the transplant waitlist?

Stay healthy, eat well, exercise, and get plenty of rest. The transplant team's dietitian can help you with your diet.

Continue routine visits with your family doctor and any specialists you have. These healthcare providers will continue to care for you while you are on the waitlist. You are responsible for making appointments and continuing your lab work as instructed by these healthcare providers.

Some of your evaluation testing will need to be repeated while you are on the waitlist. Your transplant team will tell you which tests need to be repeated and how often.

Contact your transplant coordinator by phone (leave a message) or email during regular working hours about any of the following:

- changes in your current health conditions
- new infections or illnesses
- new medicines or changes to your medicines
- admissions to a hospital
- if you receive blood products
- worsening of your symptoms
- if you are planning to travel
- any change in contact information for you or your support person (including phone numbers, address, email address)
- any change of support person

If there is a change in your health and you no longer meet the criteria for a liver transplant, or if it's not in your best interest, you may be put on hold or be removed from the transplant waitlist. Your transplant team will talk to you if this needs to happen.

Waiting for a transplant is difficult. Your transplant team is here to support you and work together towards the goal of transplant. Stay positive! Reach out to friends and family for extra support.



For parents and guardians: Preparing a child for transplant surgery

Tell your child the truth, as much as they will understand, before they come to the hospital. You may want to tell your child:

- what the surgery cut will look like (draw a picture of the cut on their stomach)
- they will have some pain, but they can ask for medicine to make it feel better
- the doctors, nurses, and the Child Life team are there to help make them better



Your child might find it helpful to read about the transplant experiences of another child, like in the books:

- Pennies, Nickels & Dimes, by: Elizabeth Murphy-Melas
- Precious Gifts: Katie Coolican's Story: Barklay and Eve
- Explain Organ and Tissue Donation, by: Karen L. Carney

Find more information about [preparing your child for surgery](#).



For parents and guardians: Waiting for a call

A mobile device (cellphone or smartphone) is the best way for the program to reach you.

- Carry your mobile device with you at all times.
- Make sure your voicemail is set up.
- Calls with an organ offer often show as unknown numbers or private. Make sure you answer these calls and do not block unknown numbers on your phone.
- Save important phone numbers to your mobile device, like your liver transplant program, your insurance provider, and your support person.
- Talk to your transplant team if you don't have a mobile device.

How can I plan for a transplant?

Transplants can occur at any time on any day. The transplant program needs to be able to contact you or your parent or guardian 24 hours a day when an organ becomes available. If you do not answer your phone, you may miss your chance for a transplant.

Keep a bag packed and ready for your trip to the hospital. Make sure to include:

- your healthcare card and picture ID (if you have one)
- medicines
- toiletries (deodorant, toothbrush, toothpaste, and comb or brush)
- slippers, comfortable clothing, and shoes for activity (if you would like to wear your own pajamas, pack those too)
- your favourite toys, books, magazines, music, and some pictures of your family and pets (any items of comfort)
- chargers for any electronic devices

Do not bring any jewelry or valuables to the hospital with you.

Your parent or guardian can keep a small amount of money in case you need it while you are in the hospital.

Mark all personal items with your name.

Pack as much as you can ahead of time. Keep a list of items you cannot pack ahead of time and any last-minute tasks (like people to call or things to do) on top of your packed bag.

If you are not from Edmonton, your parent or guardian will also need to have a bag packed with a last-minute list of things to pack and do.



For parents and guardians: Other things you need to think about when planning for a transplant

Other things you need to think about when planning for a transplant include:

- Arrange for someone to get your mail, pay your bills, and take care of your children and your pets while you are away.
- Depending on where you are from, you may need to make your own arrangements and pay for transportation to the hospital.
- Have a plan for accommodations for the time you and your support person are staying in Edmonton.



For parents and guardians: Packing for the hospital for younger children

The hospital will provide pajamas, diapers, and food for your child. Parents and guardians are responsible for their own food.



Bring:

- pajamas for your child if they would like to wear their own
- your child's favourite toys, books, magazines, or music
- pictures of family or pets, or other favourite reminders of home (the more your child feels at home and has things to do, the faster the recovery will seem)
- bottles, formula, nipples, and favourite soothers (for babies)
- feeding supplies (if tube fed) and feeding pump
- any medicines your child is taking at home
- thermometer (you will need this when you leave the hospital after your transplant)

How can I cope while waiting for a transplant?

If you are feeling stressed, you are not alone. Waiting for a liver transplant may cause fear, anxiety, and feelings of being overwhelmed.

To help you through this time:

- Do not use substances for coping.
- Know and understand your health condition. Ask questions.
- Talk about your health condition and health decisions with trusted, knowledgeable people, such as your transplant team.

If you are feeling stressed, you are not alone. Waiting for a liver transplant may cause fear, anxiety, and feelings of being overwhelmed.

- Use your friends and family for support.
- Take time for yourself.
- Keep doing your normal daily activities and exercises within your limits.
- Set goals that keep you as independent as possible.
- Enjoy some relaxing hobbies or activities.
- Learn and practice relaxation methods.
- Ask your transplant team about local support groups in your area.
- Talk to your family doctor or pediatrician.

If you or your family need additional support to cope, ask your transplant team about being referred to someone, or contact the following resources:

- Call Kids Help Phone at 1-800-668-6868 or text CONNECT to 686868.
- If you are an Alberta resident, or are staying in Alberta, you can call the Mental Health Helpline at 1-877-303-2642.
- Call or text the National Suicide Prevention and Mental Health Hotline at 988.

Visit [Help in Tough Times](#) for a list of resources that can help you.



Brennen's Story

"Feeling hopeless, there was nothing to do but wait. Our advice for this tough period is to spend as much time as you can as a family, enjoy the moment, and do not forget to do the things that you would normally do. We did as much as we could with the boys, taking them camping, swimming, and trips to the mountains. It was at this time that we also did something that really helped us through this. We were put in touch with a wonderful family who had been through what we were going through. This helped so much as they gave us an idea of what to expect and what we may feel during the wait and the transplant itself."

What happens when I get the call for my liver transplant?

Once a liver becomes available, someone from the transplant team, usually a coordinator, will contact you by phone. It may not be your own coordinator who contacts you.

There is a limited amount of time during which the liver can be transplanted. If the transplant team cannot reach you, or if you are not ready, willing, or able to accept the new liver, they will offer the liver to another person on the waitlist. The transplant team does not know how long it will be until another liver becomes available.

Learn what you need to know about [receiving the call for a transplant \(video\)](#).

The transplant team will only offer you a liver if it is suitable for you.

Exceptional distribution and increased risk donors

What is exceptional distribution?

Transplants are regulated by Health Canada.

There are strict rules for assessing and testing donor organs that can be used for transplant. This screening and testing is a lot like what happens when people donate blood.

Organs that do not meet all of Health Canada's safety rules may be accepted for transplant and offered to you under what is called exceptional distribution.

Learn more about [exceptional distribution \(video\)](#).

.....

It's best to think
about your
exceptional
distribution decision
before you're offered
an organ. Don't wait
until you get the
offer.

Some examples of releasing an organ under exceptional distribution include:

- The donor has a disease that may be passed on to you, such as an infection or a cancer.
- The donor has travelled to a place where there is a known disease risk.
- Important questions about the donor's history cannot be answered.

Organs offered under exceptional distribution may carry other risks or unknown risks to the person receiving it. These organs could, for example, have a higher risk of spreading a disease or infection to you. But the risk usually does not affect how well the organ works.

When organs are released under exceptional distribution, transplant doctors consider everything very carefully. They have decided that there are more benefits to using the organs than there are risks. Otherwise, the organ would not be offered to you.

When you're offered an organ for transplant, you will be told if it is being released under exceptional distribution. You decide if you want to move forward with the transplant.

If you do accept an exceptional distribution organ, your transplant team will watch you closely to make sure that you're safe.

If you decide not to accept the exceptional distribution organ, you will not lose your place on the waitlist, but you will have to wait for another organ. This increases your chances of getting sicker or dying while waiting for a transplant. Many organs are transplanted under exceptional distribution. The next suitable organ for you may also be under exceptional distribution.

It's best to think about your exceptional distribution decision before you're offered an organ, and not wait until you get the offer.

Talk to your transplant team if you have any questions or concerns about the risks of accepting an exceptional distribution organ.

What is an increased risk donor?

An increased risk donor is a donor who may have a higher chance of infections, including HIV, hepatitis C virus, and hepatitis B virus.

Health Canada has rules for assessing and testing these donor organs. These donors have additional special tests completed to check for these infections. Even when these test results are negative, there is a chance that the donor could have picked up one of these infections in the 7 days before testing, as it may be too early to show up in the results.

For the person getting the transplant, there may be some risk of getting an infection from an increased risk donor organ. Overall, the risk is low. You have a higher risk of dying in a car accident than getting an infection from an increased risk donor organ.

When you are offered an increased risk donor organ, transplant doctors consider everything very carefully. They have decided that there are more benefits to using the organ for your transplant than there are risks. Otherwise, the organ would not be offered to you.

When you are offered an increased risk donor organ, transplant doctors consider everything very carefully. They have decided that there are more benefits to using the organ for your transplant than there are risks. Otherwise, the organ would not be offered to you.

When you are offered an organ for transplant, you will be told if your donor is an increased risk donor. You decide if you want to move forward with the transplant.

If you decide not to accept the increased risk donor organ, you will not lose your place on the waitlist, but you will have to wait for another organ. This raises your chances of getting sicker or dying while waiting for a transplant. Many organs are transplanted from increased risk donors. The next suitable organ for you may also be from an increased risk donor.

If you do accept an increased risk donor organ, your transplant team will watch you closely to make sure you're safe. You'll have blood tests at 1 month, 3 months, and 12 months after your transplant to watch for any infections. If an infection happens, which is rare, treatments are available, and you would be treated by a team of specialists.

It's best to think about your decision for increased risk donor organs before you're offered the organ and not wait until you get the offer.

Learn more about [increased risk donors \(video\)](#) and talk to your transplant team if you have any questions or concerns about the risks of accepting an increased risk donor organ.

Liver transplant surgery

What happens after I accept the offer?

Keep your mobile device with you and keep your phone line free. The transplant team may need to call you again. Call your support person and have them make any other phone calls for you so that your phone line stays open.

The transplant team will:

- tell you when to stop eating and drinking
- need to know if you have a central line, are on I.V. nutrition, or are tube feeding
- tell you if you should continue to take your regular medicines
- talk with you about how you are getting to the hospital. How far away you live and the timing of the transplant will determine how you get to the hospital.



For parents and guardians: Getting to the hospital

To get to the hospital, you may need to drive, take a ground ambulance, or take an air ambulance. Depending on where you are coming from, you may need to pay for some of the cost.



If you are being sent by ground or air ambulance, one parent or guardian can travel with their child. Other parents or guardians and support people will have to find their own transportation.

If you are driving to the hospital, tell the transplant team if there will be any delays in you getting there.

You need to book accommodations for the time you, your parent or guardian, and support person will be in Edmonton. If you need assistance, a social worker is available during regular office hours to help guide you. They can give you a list of recommended accommodations. You may be responsible to pay for all or part of your own living costs while in Edmonton.

Where do I go to get my liver transplant?

Liver transplants are done in Edmonton. For children and teens (under 18 years old), you will go to the Stollery Children's Hospital. The transplant team will give you instructions on where to go when you arrive at the hospital.

Is there a reason my transplant may be cancelled?

At any point in time after you have been offered an organ, the transplant may be cancelled.

In some cases, after you arrive at the hospital, the transplant team might decide that doing the transplant is not safe or not in your best interest. This is called a “dry run.”

If the transplant is cancelled because of a problem with the donor, you will stay on the waitlist and wait for another liver. If the transplant is cancelled because you have a health issue, the transplant team will need to make sure it is safe to put you back on the waitlist.

While this may be disappointing, this gives you a chance to see what happens when you are called for transplant and can reassure you that transplants are happening. It may help you be more prepared the next time you get called.

You may be discharged right away or have to stay in the hospital for a few days.

Sometimes, people can have several dry runs.

If you or your family members experience any coping difficulties following a cancellation or dry run, reach out to your transplant team.



For parents and guardians: Returning home after a dry run

In the event of a dry run, you are responsible for finding and paying for your transportation home.

What will happen at the hospital before my transplant?

Before your transplant, you will:

- have blood and urine tests
- have a chest x-ray
- complete other tests as needed
- have an intravenous line (I.V.) inserted (this is a tube inserted into your vein with a needle)
- take a shower using special surgical soap
- review consent forms for your parent or guardian to sign

What happens during the surgery (in the operating room)?

The [Your Surgery Journey video series](#) and [Your Child's Surgery](#) can help you get ready for surgery and explains what happens at different steps.

Before your surgery, a specialist called an anesthesiologist will ask you some questions. When you are in the operating room, they will give you medicine to make you sleep and keep you comfortable during the surgery.

After you are in the operating room, the following tubes and lines will be placed:

- Intravenous (I.V.) lines to give you fluid and medicines.
- Central lines to measure how much fluid you have in your body and the pressure in your heart. These are also used to give medicines.
- Arterial line to measure your blood pressure and take blood samples.
- Breathing tube attached to a breathing machine (ventilator).
- Nasogastric tube to give medicines and drain the contents of your stomach.
- Foley catheter to drain urine (pee) from your bladder and monitor your kidney function.
- Drains to remove blood and body fluids from around the surgical area.

During a liver transplant, your diseased liver and your gallbladder will be removed and replaced with a healthy donor liver.

How long the surgery takes can be different for everyone but is usually 6 hours or longer.

Staples or stitches will hold your incision (cut) together and will stay in place until your incision heals. A large bandage called a dressing protects your incision and will be changed by your nurses as needed.

What are the common problems of liver transplant surgery?

Problems from the surgery can include:

- bleeding more than expected
- blood clots
- infection
- the new liver doesn't work properly right away

The transplant team will watch you carefully for any problems.

After your liver transplant surgery

Where do I go after my surgery?

After your transplant surgery, you will go to the pediatric intensive care unit (PICU). How much time you spend in the PICU is different for everyone.

Once you are strong enough and your breathing tube has been removed, you will be moved back to the unit where you were first admitted and had your evaluation.

After a liver transplant, everyone stays in the hospital for a different amount of time. Your transplant team will decide when you are ready to go home.



Brennen's Story

"When we arrived at the hospital we were told that his surgery wasn't until the next morning so we sat and held him all night and cried. We told him how much we loved him and that it was going to be okay even though we weren't sure. His surgery lasted 8 hours and went as good as they could have hoped for. When we got to see him in PICU it was heartbreaking. He was attached to so many monitors and had tubes coming out of everywhere, it is something that as a parent you never want to see. We were just amazed that this tiny little body could go through so much. As we sat by his bedside in those first 24 hours something amazing happened. We literally saw the yellow drain from his body. He actually had pink feet! We have never been so thrilled in our lives to see pink feet."

What can I do in the hospital after my surgery to help with my recovery?

- Follow the instructions of your healthcare team.
- Ask for medicine when you are in pain.
- Practice [deep breathing and coughing techniques](#).
- Change positions in bed and keep moving your arms and legs. Moving helps to prevent problems like pneumonia, bowel problems, and blood clots.
- Make sure you talk with your bedside nurse about how to move safely with your lines and tubes in place.
- Work with the physiotherapist and nurses to help regain your strength.
- Work with the occupational therapist to help you get back to your daily activities.
- Tell your nurses and transplant team right away if you notice any changes in your condition.

Your parents or guardians will be encouraged to be with you and participate in your care to help with your recovery. Visiting hours for parents and guardians are 24 hours a day. One parent or guardian can sleep at your bedside.

You and your parents or guardian will have multiple teaching sessions with the pharmacist, transplant coordinator, dietitian, nursing staff, physiotherapist, and occupational therapist in the hospital to get you ready for discharge.

Your healthcare team will teach you and your parents or guardians about your medicines and you will start giving yourself the medicines while you are in the hospital with directions from the nurses. This will help you become familiar with the number of new medicines you will need to take at home.

The transplant journey can be stressful and overwhelming. Talk to your transplant team if you or your family need help coping. Your post-transplant team can refer you to a mental health specialist if needed. Visit [Help in Tough Times](#) for a list of resources that you can access when you're feeling stressed or are having a difficult time.

When will I be able to leave the hospital?

After a liver transplant, everyone stays in the hospital for a different amount of time.

You will leave the hospital when:

- The transplant team decides that you are medically and physically well enough to be discharged.
- You or a family member have learned how to take your own medicines.
- You or a family member are able to recognize the signs of infection and rejection.
- You have received and read your post-transplant material and watched the [videos on cytomegalovirus \(CMV\), Epstein Barr virus \(EBV\), and increased risk donors \(IRD\)](#) (if applicable).

What do I need to do on the day I leave the hospital (day of discharge)?

On the day you leave the hospital, make sure that you and your parent or guardian have:

- picked up your medicines and reviewed them with your transplant team
- received new lab requisitions and information about where and when to get your lab tests done
- received follow-up appointment information
- reviewed your After Visit Summary (AVS) with your nurse or transplant coordinator
- someone available to drive you from the hospital

Make sure you have the following items:

- thermometer that measures in Celsius
- blood pressure monitoring machine
- blood glucose monitoring machine (if needed)
- notebook, app, or computer document to record your temperature, what you drink, and what you pee

Leaving the hospital and managing your health after your liver transplant

What happens after I leave the hospital?

Getting a transplant means a lifetime commitment to medical treatments, like taking many medicines every day (every 12 hours or daily), going to clinic appointments, and doing regular bloodwork and other tests. This is to prevent rejection and minimize other potential complications.

If you live outside of the Edmonton area, you and your parent or guardian should be prepared to stay in Edmonton for 3 months.

Your transplant team will follow you closely. Your follow-up appointments and tests may take up a lot of time.

Make sure you and your parent or guardian and support person have a way to get to and from your appointments.

You will need to take time off school or work during the recovery period. Talk with your transplant team about when you can safely return to school or work. The length of the recovery period can be different for everyone.

You will need to go to appointments to see your surgeon and liver specialist. How often you visit the clinic depends on your medical needs. There will be many visits during the first year. For your clinic visits, have the following ready to bring with you:

- your medicines for the day
- your medicine list
- your records of what you drink and pee
- your diabetes records (if you have diabetes)
- your list of questions, concerns, or changes you want to discuss

Getting a transplant means a lifetime commitment to medical treatments, like taking many medicines every day (every 12 hours or daily), going to clinic appointments, and doing regular bloodwork and other tests.

You will go for many blood tests after you leave the hospital. How often you need bloodwork goes down over time. Blood tests must be done early in the morning, before you take your medicines. Having these tests is how your transplant team monitors your anti-rejection medicine levels and signs of any other medical problems. Your transplant coordinator will review your test results with your transplant doctors and let you know if any changes are needed.

To monitor your transplant, you may also need other procedures like a [biopsy](#), [ultrasound](#), percutaneous transhepatic cholangiogram (an x-ray of your bile ducts that uses dye to check for problems), [CT scan](#), or [MRI](#).

You may need to attend physiotherapy and occupational therapy appointments.

Things to remember:

- Do not lift anything heavier than 10 pounds for 3 months after your surgery. This may include heavy grocery bags, milk containers, a heavy backpack, cat litter or dog food, a vacuum cleaner, or another child.
- Do not immerse your incision (surgery cut) in water for 3 months after your surgery or until the incision is fully healed, whichever is longer.
- Do not immerse your peripherally inserted central catheter (PICC) line in water. Cover and protect it with a waterproof dressing when showering.

If you live outside the Edmonton area, your care will be transferred back to your home program once you are physically and medically well enough. Your transplant team will share your transplant information with your home program.

As your recovery continues, your liver transplant team will start to focus on the medical issues directly related to your liver transplant. Your family doctor or pediatrician will continue supporting your overall health. The transplant team and your family doctor or pediatrician will communicate with each other.



Brennen's Story

"The first few months seemed like a blur of trying to keep up with all the post transplant care. By three months post transplant when things had settled down quite a bit and Brennen's liver was still working great, everything finally hit. We began to feel the emotional and physical exhaustion of having a child with a transplant. You are so focused on getting your child to transplant and helping them recover, and being there for them every second that you put aside the incredible toll that this takes on you as a parent."

What can I do to help with my recovery and overall health?

Some general recommendations to help with your recovery and overall health include:



- Eat a balanced diet and maintain a healthy weight. Your transplant dietitian can help you.
- Drink the amount of fluids recommended by your transplant team. This helps keep your kidneys healthy.



- Exercise regularly following the guidelines that your physiotherapists and doctors give you.



- Do not drink alcohol.
- Avoid all tobacco, nicotine, or cannabis products, smoking or vaping any substance, and using street drugs.
- Tell the transplant team if there are any changes in your medical condition or the medicines you take.



- Check with your transplant team before taking any over-the-counter vitamins, medicines, herbal products, supplements, or medicines prescribed by anyone other than your transplant team.

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If you have specific concerns about your recovery or overall health, talk with your transplant team.



- When going outside, wear a hat and sunscreen (minimum SPF 30) and do not get a sunburn. Avoid tanning beds. The medicines needed to prevent rejection of your transplant increase the risk of skin cancer.



- Take good care of your teeth and mouth. Examine your mouth every day, before you brush your teeth, for sores or white spots. These may be signs of a viral infection, or a yeast infection called thrush. If you notice any sores or white spots, call your transplant team. You will take medicines for at least 6 months after your transplant to help prevent this.



- To avoid the risk of infection, do not have any routine dental work done in the first 6 months after your transplant. After the first 6 months, continue to see a dentist regularly. Before any major work on your teeth or mouth, call your transplant team.



- Keep seeing your family doctor, pediatrician, and any other healthcare providers for your general healthcare needs.
- See your eye doctor (optometrist) for routine checkups.
- Stay up to date on your regular cancer screenings (prostate, colorectal, breast, cervical, and skin cancer). Anti-rejection medicines can increase your risk of some types of cancer.
- Buy a medical alert bracelet or necklace that says you had a liver transplant, are immunocompromised (you take anti-rejection medicines), and lists any other health conditions you have. You can also put this information in your wallet, on your mobile device, or in a health app. Talk to your transplant team before buying a bracelet or necklace.
- Avoid getting tattoos after your transplant. If you still choose to get a tattoo, tell your transplant team and make sure you are being [as safe as possible](#).



Travel is not recommended outside of Canada for the first year after your transplant. Call your transplant program before travelling to make sure you don't have any tests or appointments booked during your travel time. Check if any immunizations are needed before you travel. Always talk to your transplant team before getting any immunizations, especially live vaccines. Consider travel insurance when making travel plans, even if your travel is within Canada.

When travelling, always bring enough medicine for the length of your trip and 2 weeks of extra medicine in case of delays. Keep medicines in your carry-on bag. A letter can be provided to you to help you take your medicines through security and customs. Give your transplant coordinator time to prepare the letter for you.

You may experience new emotions or feelings as you adjust to life after transplant. You can:

- Use the coping tips from when you were waiting for your transplant.
- Ask your transplant team about being referred to someone to help you cope during these times.
- Call Kids Help Phone at 1-800-668-6868 or text CONNECT to 686868.
- Contact the Mental Health Helpline at 1-877-303-2642 if you are an Alberta resident or are staying in Alberta.
- Call or text the National Suicide Prevention and Mental Health Hotline at 988.
- Visit [Help in Tough Times](#) for a list of resources that can help you when you are feeling stressed or having a difficult time.

If you have specific concerns about your recovery or overall health, talk with your transplant team.

How can I avoid getting sick after my liver transplant?

After your transplant, you have a higher chance of getting an infection.

It is important to take steps to protect yourself, like:

- Wash your hands with soap and water, and have your family and friends wash their hands frequently.
- Avoid contact with people who are sick.
- Try to avoid crowded places, especially in the first 3 months after transplant, during respiratory virus season (usually the fall and winter months), and for 3 months after being treated for rejection.
- Consider wearing a mask in crowded places.
- Stay up to date on all immunizations. Talk to your transplant team before getting any immunizations, especially live vaccines. Encourage family members to keep their immunizations up to date.
- Take good care of your teeth and gums and have regular dental exams and cleanings. Talk to your transplant team about the need for antibiotics for any dental appointments. Do not have any routine dental work done in the first 6 months after your transplant.

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After your transplant, you have a higher chance of getting an infection. It is important to take steps to protect yourself.

- Protect yourself from mosquito bites to prevent West Nile virus. You can do this by avoiding being outside at dusk and dawn, wearing light clothing including long sleeves and pants, and by using mosquito repellent with DEET.
- Avoid playing or working in the dirt for 6 months after your transplant. After 6 months, wear gloves, pants (not shorts), and other coverings to protect your skin from contact with the dirt. Wear a mask when mulching or digging in the dirt and generating dust.
- Avoid other activities that create a lot of dust.
- Take steps to prevent [sexually transmitted infections](#).
- Avoid touching animal waste and cleaning animal cages, fish or turtle tanks, and litter boxes. If you must handle or clean up animal waste, including mouse droppings, wear gloves and a mask. Keep your pets' vaccinations up to date.
- Try to avoid your pet being close to your face, nose, and mouth, especially with their mouth. Don't let your pet or other animals lick your open wounds. Some pets should be avoided. Talk to your transplant team for a list of these animals.
- Wash or peel fruits and vegetables and follow [safe food handling practices for immunocompromised individuals](#). Do not eat raw or undercooked eggs, meat, fish and seafood, hot dogs, deli meats, or sprouts. Have only pasteurized milk and milk products, juices, ciders, and honey. Do not drink water from lakes or rivers. Talk to your transplant team about well water.
- Disinfect kitchens, bathrooms, and high-touch spots often. Change kitchen and bathroom linens frequently.

Watch for possible signs of infection:

- temperature greater than 38°C (if you are taking prednisone, watch for a temperature of 37.5°C or higher)
- sweating, chills, and shaking
- shortness of breath
- cough that creates [mucus](#)
- sore throat or runny nose
- pain, change in skin colour, or swelling anywhere on your body
- change in colour, amount, and smell (odour) of your urine (pee) or stool (poo)
- burning when you pass urine (pee)
- open sores or wounds that have drainage
- nausea, vomiting, or diarrhea

You will be given medicines for a period of time after your transplant to help prevent common infections after transplant.

Call your transplant team or pediatrician to report signs of infection. If they are not available, call the nurse advice line in your area (in Alberta, call Health Link at 811).

If you have trouble breathing, belly (abdominal) pain, uncontrolled high fever, irritability, are more sleepy and clingy, are not eating or drinking, or any other severe symptoms, go directly to your nearest emergency department.

What is rejection?

Rejection happens when the transplanted liver is attacked by your own immune system. The best way to prevent rejection is to take your anti-rejection medicines on time, take the right dose, and complete lab work as scheduled.

It is very important to watch for any signs of rejection so that your doctor can treat it quickly. Possible signs of rejection may include:

- fever
- fatigue or weakness
- belly (abdominal) pain
- nausea, vomiting, or diarrhea
- [jaundice](#) (yellowing of your skin and eyes)
- increased liver enzymes (this will show in a blood test)

Rejection is often discovered by your bloodwork results before any symptoms appear. If the transplant team thinks you have rejection, you may need a liver ultrasound and a liver biopsy. A biopsy is a procedure where a needle is used to take a small sample of your liver for testing. You are admitted to the hospital for a biopsy and you are given medicines to keep you comfortable. If rejection is confirmed or suspected, your transplant team may increase the doses of your anti-rejection medicines or give you different medicines.

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The best way to prevent rejection is to take your anti-rejection medicines on time, take the right dose, and complete lab work as scheduled.

Some patients need to be admitted to the hospital for further diagnosis and treatment.

Rejection can happen at any time. Talk with your transplant team if you have any questions or concerns about rejection.



Brennen's Story

"His bilirubin and liver function numbers began to come down almost immediately. We felt like our prayers had been answered, our little boy was doing great but we still were so worried about rejection.

Those first few days we only left Brennen's side to eat a quick meal or sleep a few hours. But as the days went on Brennen became more alert and responsive. Within a week he began to laugh again."

What can I know about the donor?

When you receive a liver transplant, the liver is given to you without the donor's name, sex, age, location, or any other details. This is to protect information about you, the donor, and the donor's family.

If you want to write to your living donor or your deceased donor's family, there is a letter writing process to say thank you. In most cases, donors and donor families are happy to get these letters.

The transplant team will check your letters to make sure they follow privacy rules. They will let you know if anything needs to be changed. If you need help writing a letter, ask your transplant team.

Medicines after your liver transplant

What kind of medicine will I need to take after my liver transplant?

[Anti-rejection medicines](#) (also called immunosuppression medicines) prevent your immune system from attacking the transplanted liver. Anti-rejection medicines include:

- [tacrolimus](#) (common brand names: [Prograf](#), [Advagraf](#), or Envarsus)
- [mycophenolate mofetil](#) (common brand name: [Cellcept](#))
- [sirolimus](#) (common brand name: [Rapamune](#))

You will need to take anti-rejection medicines every day (every 12 hours or daily) for the rest of your life.

Not taking these medicines as instructed, or missing doses, can lead to rejection, which can cause your liver to not work properly.

Take these medicines at the same time of day that you took them in hospital. Never stop taking these medicines or change your dose without first talking to your transplant team.

Always have at least a 2-week supply of medicines and never let yourself run out.

When you take anti-rejection medicines:

- You will need to get bloodwork done often to monitor your medicine levels.
- Your blood tests must be done before you take your anti-rejection medicines.
- Talk with your transplant team before taking any over-the-counter vitamins, medicines, herbal products, supplements, or medicines prescribed by anyone other than your transplant team. Many other medicines can interact with anti-rejection medicines.
- Ask your transplant team which medicines you can take for pain or fever.
- Never take non-steroidal anti-inflammatory medicines (NSAIDs) like ibuprofen (Advil, Motrin), naproxen (Naprosyn, Aleve), diclofenac (Voltaren), and indomethacin.

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You will need to take anti-rejection medicines every day (every 12 hours or daily) for the rest of your life.

- Some foods will interact with your anti-rejection medicines. Talk to the transplant team to learn more about which foods to avoid.
- Tell your pharmacist, dentist, and all other healthcare providers that you are taking anti-rejection medicines.
- Talk to your transplant team about when to take your anti-rejection medicines if you are travelling to different time zones.
- Do not get pregnant or get someone pregnant while on anti-rejection medicines without first talking to a member of the transplant team. Ask the transplant team about using birth control, as some forms of birth control work better with anti-rejection medicines than others.
- Anti-rejection medicines can increase your risk of some types of cancer. For more information, talk to the transplant team.

There are other medicines you might also need to take:

- medicines to protect your stomach from ulcers
- antacids (but do not take antacids within 2 hours of taking any anti-rejection medicines)
- antibiotics, antivirals, or both to help protect you against infection
- water pill (also known as a diuretic) to help your body remove extra fluid
- medicines to keep up with essential nutrients like calcium, magnesium, or iron
- medicines to prevent pneumocystis pneumonia, including [sulfamethoxazole-trimethoprim](#), atovaquone, or pentamidine (common brand names of these medicines are Sulfatrim, [Septra](#), Bactrim, Co-Trimoxazole, and Mepron)
- medicines to prevent or treat cytomegalovirus (CMV), including [valganciclovir](#) (common brand name: Valcyte)
- medicines to prevent or treat herpes virus infections, including [valacyclovir](#) (common brand name: Valtrex)
- medicines to prevent or treat fungal infections
- medicines to promote bone health (vitamin D, multivitamins)

You or your parent or guardian are responsible for making sure you get and take your medicines. Talk to your transplant team to understand:

- the name and reason for each medicine
- when to take each medicine
- how to take each medicine
- how to store each medicine
- side effects of each medicine
- what to do if you forget to take a dose
- when and how to order more medicines so you don't run out



Brennen's Story

"When we took Brennen home after his transplant, it was just like taking a newborn home again, both excitement and fear. We were so happy to be able to be a family again with our other son. But on the other hand I was very scared. Being the one home with him all day and in charge of his care, I was so worried that I would forget to give him one of his many, many meds, or that he would begin to reject and I wouldn't recognize it in time. To help alleviate some of this fear we developed a calendar of his daily meds, which we would check off as we gave them to him, allowing both of us to be able to give him his meds without missing or doubling up on a dose."

Is the cost of transplant medicines covered by Alberta Health?

Alberta Health covers the cost of anti-rejection medicines for Alberta residents. Similar programs are available for people from other provinces.

Other medicines you need after transplant can be very expensive. Depending on your drug insurance plan, you may have to pay some of the cost on your own. Talk with your social worker to make sure you have medicine coverage in place.



Brennen's Story

"Brennen is now at 7 months post transplant and we just celebrated his first birthday. It was such a great day for our family. There were times in this last year that we didn't know if we would make it to this point, but here we are and life actually seems fairly normal. Every day we still think about all that we have been through and worry about Brennen's future, but the painful memories are not as strong as they once were. We only have blood work twice a month and doctor visits monthly. For the first time in just about a year, we actually have weeks off without a weigh-in or blood work or doctor visits or some sort of test or procedure. It truly makes you appreciate how wonderful a normal life can be."

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