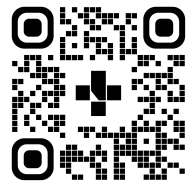


Pediatric Heart Transplant Education Manual

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



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Who is this guide for?

This guide is for parents and guardians of infants, children, and teens (under 18 years old). It will help to answer your questions about heart transplants for your child.

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 child's heart transplant, talk with their primary healthcare providers or the heart transplant team.

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

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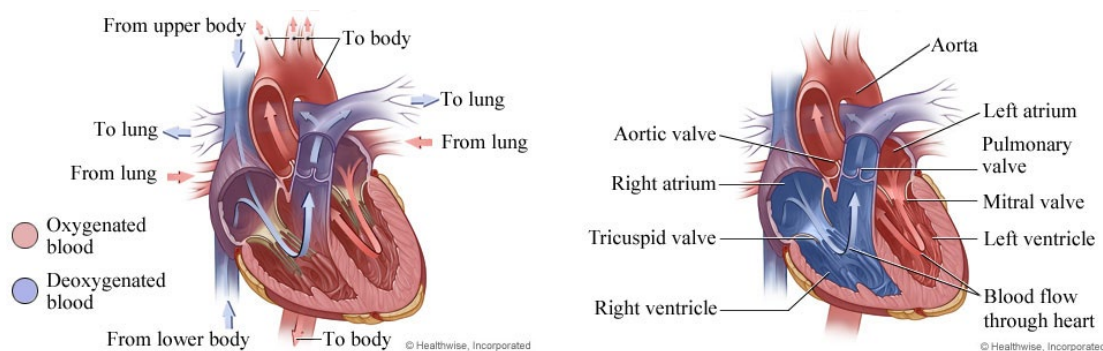
If you have any questions about your child's heart transplant, talk with their primary healthcare providers or the heart transplant team.

About heart transplants

What does the heart do?

The heart is a muscle. Its main job is to keep blood flowing smoothly through your body. The right side of your heart receives the blood coming from your body and pumps it to your lungs. The left side of your heart receives blood from your lungs and pumps it to your body. Learn more about [how the heart works](#).

Some children are born with problems with the structure of their heart. This is called congenital heart disease. How the blood flows through their heart may be different.



Who can get a heart transplant?

A heart transplant may be considered as a treatment option for children with certain types of heart disease and end-stage heart disease. End-stage means your child's heart may no longer be able to keep them alive and there are no more treatments to help your child's sick heart.

The most common reasons children need a heart transplant are:

- complex heart defects present at birth (congenital heart disease)
- poor heart function caused by an abnormal heart muscle (cardiomyopathy)

Children can be born with an abnormal heart muscle, a virus can cause an abnormal heart muscle, or sometimes the cause is unknown.

A heart transplant may be an option when your child's heart isn't getting better with medicines or surgery.

In some cases, a [ventricular assist device \(VAD\)](#) may be used as a bridge to transplant. This means your child can get stronger and healthier using a VAD before a transplant happens.

Who can donate a heart?

Your child's new heart comes from a deceased donor (someone who has died).

Heart transplants are limited by the number of donors available. There are not enough deceased donors for everyone.

Is a heart transplant right for my child?

A heart transplant is not right for everyone. It is also not a cure. 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 your child has heart disease that is severe enough to need a transplant, and all other treatment options have been tried. Their body must also be strong enough to tolerate the surgery and recovery.

Depending on your child's health history, a heart transplant may not be an option for them. The transplant team will discuss this with you.



For older children and teens:

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 heart 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.

Does my child need a support person?

Yes. Your child **must** have a parent or guardian to support them throughout all phases of their transplant journey: evaluation, waitlist, surgery, recovery, and follow-up.

This is a very challenging situation for any family. It's also good for your family to have other support people to help your child and you (the parents or guardians) when needed.

If you live outside of the Edmonton area, your child and a parent or guardian should be ready to stay in Edmonton for up to 3 months after your child's transplant. If you live in a remote community, you may need to stay in Edmonton for 1 year or longer.

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Your child **must have a parent or guardian to support them throughout all phases of their transplant journey.**

Parents or guardians and support people will need to:

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

You are encouraged to be with your child and participate in their care to help with their recovery. Visiting hours for parents and guardians are 24 hours a day. One parent or guardian can sleep at the bedside. Siblings can visit but are not allowed to stay overnight.

How can my family cope during the transplant process?

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

To help you and your child through this time:

- Know and understand your child's health condition. Ask questions.
- Talk about your child's health condition and health decisions with trusted, knowledgeable people, such as your child's transplant team.
- Talk with the Child Life Specialist at the hospital.
- Talk to friends and family for support.
- Take time for yourself.
- Keep doing normal daily activities and exercises within your limits.
- Set goals that keep your child as independent as possible.
- Enjoy some relaxing hobbies or activities.
- Learn and practice relaxation methods.
- Ask your child's transplant team about local support groups in your area.
- Talk to your child's family doctor or pediatrician.
- Do not use substances for coping.

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If you or your child are feeling stressed, you are not alone. Waiting for a heart transplant may cause fear, anxiety, and feelings of being overwhelmed. Support is available.

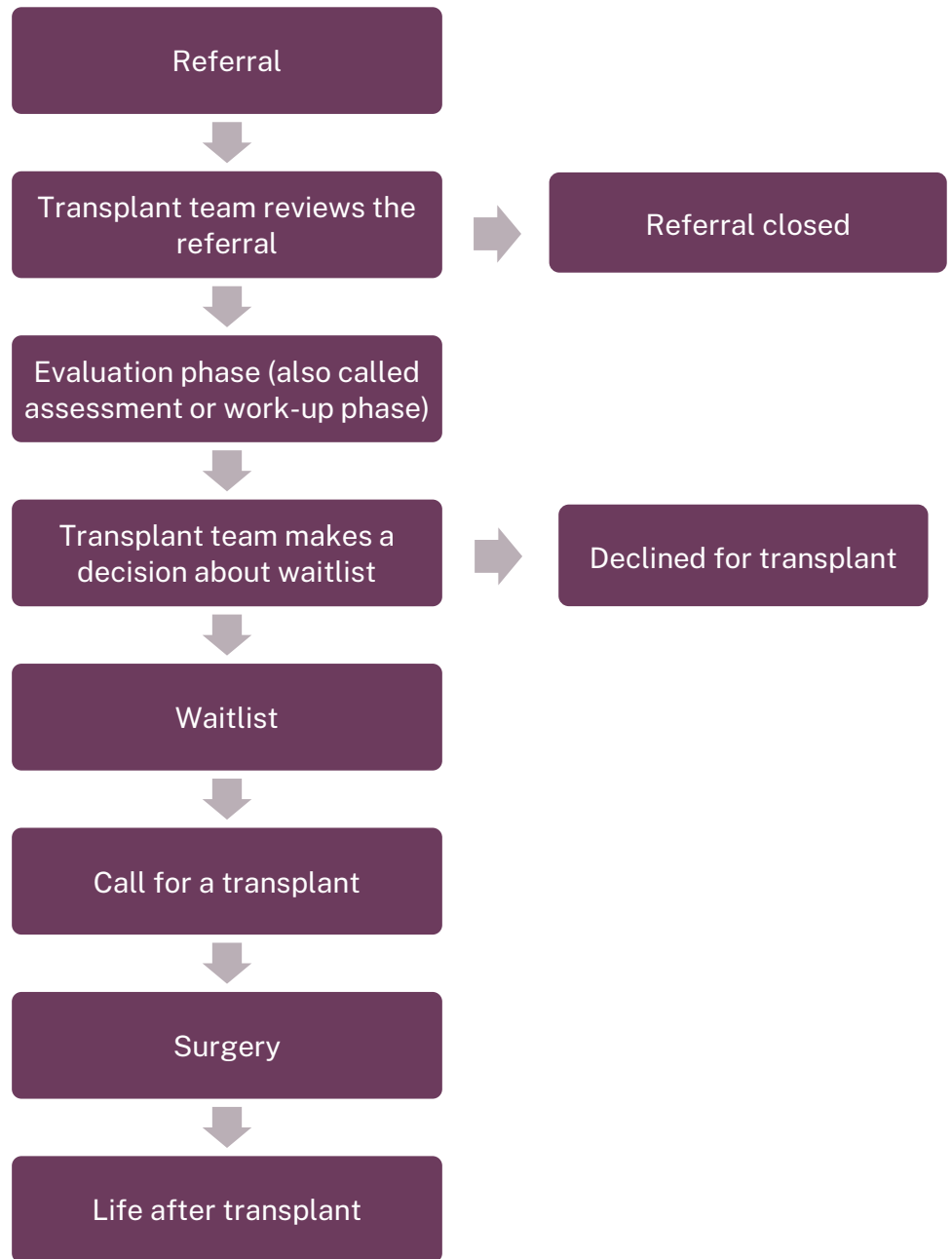
If you, your child, or your family need additional support to cope, ask your child's transplant team about being referred to someone, or contact the following resources:

- 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 988: Canada's Suicide Crisis Helpline any time, day or night.

Visit [Recovery Alberta](#) for a list of resources that can help you.

Transplant process

Overview



Referral

How does my child get referred to the Heart Transplant Program?

A heart specialist (pediatric cardiologist) can refer your child to the Heart Transplant Program.

What will happen after my child's referral has been reviewed?

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

Your child will either move on to the evaluation phase of the process, or their referral will be closed. You will have a meeting with the team to explain the decision and answer your questions. Every case and experience is different.

Evaluation

What happens in the heart 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 your child.

In most cases, your child will have to stay in the hospital for a short period of time to have their evaluation done. Their hospital stay may be longer if the heart doctors (cardiologists) need to change any of their treatments. If you live outside of Edmonton, the transplant team can help you find a place to stay near the hospital.

Your child will be assigned a heart transplant coordinator who will guide you through the evaluation process and let you know about what happens next. Heart transplant coordinators are registered nurses who are a part of the transplant team.

You and your child will meet with the transplant social worker who will help with many concerns you have about transplant.

During your evaluation, your child will:

- have many tests, like x-rays, ultrasounds, blood and urine tests, and heart tests like an [echocardiogram](#) (echo), [electrocardiogram](#) (ECG), and, if needed, a [heart MRI](#), and [cardiac catheterization](#). Your child may need to be put to sleep for some of these tests.
- meet with other healthcare providers and members of the transplant team like transplant coordinators, transplant doctors, dietitians, occupational therapists, physiotherapists, social workers, psychiatrists, dentists, infectious disease doctors, kidney doctors (nephrologists), chronic disease and palliative care team, and other specialists as needed.

If they need it, your child will have support with tests and procedures from the Child Life team.

During the evaluation phase, you will also need to:

- Make sure your child's immunizations (vaccines) are up to date. The pediatric infectious disease team will review your child's immunization record. Your child may need to get some immunizations earlier than the typical schedule. Talk to your child's transplant coordinator before they get any immunizations.
- Make an appointment for your child to see their dentist. Get any recommended dental work done before your child is put on the waitlist for a transplant.



Dental work

Try to have any dental work completed in your home province before your child's transplant. You will need a letter from your child's dentist confirming there are no signs of infection or dental concerns. There is a cost to have dental work completed. It is a good idea to have dental coverage.

Your child is not on the transplant waitlist when they finish their evaluation appointments. The transplant team needs to review all their information and discuss their case first. The transplant team will let you know if a heart transplant is right for your child.

If the transplant team decides a transplant is your child's best treatment option, and you agree, your child will be placed on the transplant waitlist. Learn more about being on the [transplant waitlist \(video\)](#).

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

The waiting time for a heart can vary from days to months to years. How long your child waits on the waitlist depends on factors like their blood type, body size, and how sick they are. It does not only depend on how long they have been waiting. The transplant team will give you details specific to your child's situation.

Waitlist

What can my child and I expect while they are on the transplant waitlist?

Your child should try to stay healthy, eat well, exercise and get plenty of rest. Make sure they are taking their medicines and going to all medical appointments.

- For outpatients, your child's primary cardiac care will continue to be with their pediatric cardiologist.
- For inpatients, your child's primary care will be an ICU intensivist or a pediatric cardiologist on service.
- Your child's heart function and transplant teams will always be involved in their care, as an outpatient or an inpatient.

Continue routine visits with your child's family doctor and any specialists they have. These healthcare providers will continue to care for your child while they are on the transplant waitlist. You are responsible for making appointments and continuing to get your child's bloodwork done as instructed.

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

Contact your child's transplant coordinator about any of the following:

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

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

Waiting for a transplant is difficult. Your child's transplant team is here to support you and your child and work together towards the goal of transplant. Stay positive! Reach out to friends and family for extra support. The transplant team can also help connect you to spiritual and mental health support providers.



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 chest)
- 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

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

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 and keep it charged.
- Make sure your voicemail is set up.
- Calls with a heart offer may show **as unknown or private caller**. 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 child's transplant coordinator and the after-hours on-call number for the cardiology team at your local hospital.
- Talk to your transplant team if you don't have a mobile device.

How can I plan for my child's transplant?

Transplants can occur at any time and on any day. The transplant program needs to be able to contact you **24 hours a day** once a heart is available.

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

- your child's healthcare card
- medicines your child is taking at home
- toiletries (deodorant, toothbrush, toothpaste, and comb or brush)
- pajamas for your child if they would like to wear their own
- slippers, comfortable clothing, and shoes for activity
- your child's favourite toys, books, or music
- pictures of your family and pets or other reminders of home (the more your child feels at home and has things to do, the faster the recovery will seem)
- chargers for any electronic devices
- bottles, formulas, nipples, and soothers (for babies)
- feeding supplies (if your child is tube fed) and feeding pump
- thermometer (you will need this when you leave the hospital after transplant)

Do not bring any jewelry or valuables to the hospital with you. Mark all personal items with your child's first and last 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, you will also need to have a bag packed for yourself with a last-minute list of things to pack and do.



Other things you need to think about when planning for your child's transplant



- Arrange for someone to get your mail, pay your bills, and take care of your other 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 are staying in Edmonton.

What happens when I get the call for my child's heart transplant?

Once a heart becomes available, someone from the transplant team, usually a transplant 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 heart can be transplanted. If the transplant team cannot reach you, or if you are not ready, willing, or able to accept the new heart, they may offer the heart to another person on the waitlist. The transplant team does not know how long it will be until another heart becomes available.

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

The transplant team will only offer your child a heart if it is suitable for them.

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 your child under what is called exceptional distribution.

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

Some examples of releasing an organ under exceptional distribution include:

- The donor has a disease that may be passed on to your child, 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 your child. 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 your child.

When your child is 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 for your child, your transplant team will watch them closely to make sure they are safe.

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

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

It's best to think about your exceptional distribution decision before your child is 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 your child is 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 child's transplant than there are risks. Otherwise, the organ would not be offered to them.

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When your child is 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 child's transplant than there are risks. Otherwise, the organ would not be offered.

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

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

It's best to think about your decision for increased risk donor organs before your child is 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 for your child.

Heart transplant surgery

What happens after I accept the heart offer for my child?

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

The transplant team will:

- tell you when your child needs to stop eating and drinking
- tell you if your child should continue to take their 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 and your child get to the hospital.



Getting to the hospital

To get to the hospital, you may need to drive your own vehicle, 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 your child is 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 your child 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 child, and any support people 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 does my child go to get their heart transplant?

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

Is there a reason my child's transplant may be cancelled?

At any point in time after your child has been offered a heart, the transplant may be cancelled.

In some cases, after your child arrives at the hospital, the transplant team might decide that doing the transplant is not safe or not in your child's best interest. This is called a "dry run."

If the transplant is cancelled because of a problem with the donor, your child will stay on the waitlist and wait for another heart. If the transplant is cancelled because your child has a health issue, the transplant team will need to make sure it is safe to keep them on the waitlist.

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

Your child may be discharged right away, or they may have to stay in the hospital for a few days. In the event of a dry run, you may be responsible for finding and paying for your transportation home.

Sometimes, people can have several dry runs.

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

What will happen at the hospital before my child's transplant?

Before your child's transplant, they will:

- have blood and urine tests
- have a chest x-ray
- complete other tests as needed like ultrasounds, electrocardiogram (ECG), and echocardiogram
- have an intravenous line (I.V.) inserted for medicines before transplant (an I.V. is a tube inserted into your vein with a needle)
- take a shower or bath using special surgical soap

The transplant team will meet with you before the surgery and explain the possible problems of heart transplant surgery. Ask them if you have any questions about the surgery.

You will review and sign consent forms for your child's surgery.

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

[Preparing for your child's heart surgery at the Stollery](#) can help you and your child understand what to expect and get ready for surgery. It explains what happens at different stages.

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

After your child is in the operating room, the following tubes and lines will be placed:

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

During the surgery, your child's diseased heart will be removed and replaced with the healthy donor heart.

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

Stitches will hold your child's incision (cut) together and in most cases will dissolve on their own as the incision heals. A large bandage called a dressing protects your child's incision and will be changed by their nurses as needed.

What are the common problems of heart transplant surgery?

Problems from the surgery can include:

- bleeding more than expected
- blood clots
- infection
- heart rhythm problems
- blood pressure problems
- kidneys don't work as well as they should

Sometimes, your child's new heart needs time to rest and adjust to the body's blood flow. A machine like [ECMO](#) (a heart and lung bypass machine) or a [VAD \(ventricular assist device\)](#) may be needed to help circulate blood and allow your child's new heart to rest. Your child's doctor will talk with you if these machines are needed.

The transplant team will watch your child carefully for any problems.

After your child's heart transplant surgery

Where does my child go after their surgery?

After your child's transplant surgery, they will go to the pediatric cardiac intensive care unit (PCICU). How much time your child spends in the PCICU is different for everyone.

Once your child is strong enough and their breathing tube has been removed, they will be moved to the pediatric cardiology inpatient unit.

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

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

You are encouraged to be with your child and participate in their care to help with their recovery. Visiting hours for parents and guardians are 24 hours a day. One parent or guardian can sleep at the bedside. Siblings can visit but are not allowed to stay overnight.

You and your child will have multiple teaching sessions in the hospital with the pharmacist, transplant coordinator, bedside nurses, dietitian, physiotherapist, and occupational therapist to get ready for discharge.

Your healthcare team will teach you about your child's medicines and you will start giving them the medicines while they are in the hospital with directions from the nurses. Depending on your child's age, they may also be involved in this teaching. This will help you and your child become familiar with the new medicines they will need to take at home.

The transplant journey can be stressful and overwhelming. Talk to your transplant team if you, your child, or your family need help coping. Your child's post-transplant team can refer your child to a mental health specialist if needed.

Visit [Recovery Alberta](#) for a list of resources that you can access when you, your child, or a family member is feeling stressed or are having a difficult time.

When will my child be able to leave the hospital?

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

Your child will leave the hospital when:

- The transplant team decides that your child is medically and physically well enough to be discharged.
- You have received medicine teaching and have practiced giving your child their medicines.
- You are able to recognize the signs of infection and rejection.
- You have received post-transplant teaching from your child's transplant coordinator.
- You have 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 my child leaves the hospital (day of discharge)?

On the day your child leaves the hospital, make sure you have:

- picked up your child's medicines from the outpatient pharmacy and reviewed them with the transplant team
- received information about where and when to get your child's lab tests done
- received follow-up appointment information
- reviewed your child's After Visit Summary (AVS) with their nurse

Make sure you have the following items:

- thermometer that measures in Celsius
- notebook, app, or computer document to record your child's temperature and what they drink
- syringes for liquid medicines (if needed)

Leaving the hospital and managing your child's health after their heart transplant

What happens after my child leaves the hospital?

Getting a transplant means a **lifetime commitment** to medical treatments, like taking many medicines every day at the same time, 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 child should be prepared to stay in Edmonton for at least 3 months after the transplant. If you live in a remote northern community, the transplant team may require you to stay in Edmonton or another city with a major cardiac centre for 1 year or longer after the transplant.

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

Make sure you and your child have a way to get to and from their appointments.

Your child will need to take time away from daycare or school during the recovery period. Talk with their transplant team about when they can safely return to daycare or school. The length of the recovery period can be different for everyone.

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Getting a transplant means a lifetime commitment to medical treatments, like taking many medicines every day at the same time, going to clinic appointments, and doing regular bloodwork and other tests.

Your child will need to go to appointments to see their transplant team. How often they visit the clinic depends on their medical needs. There will be many visits during the first year. For your child's clinic visits, have the following ready to bring with you:

- your child's medicines for the day
- your child's medicine list
- records of how much your child drinks each day
- your list of questions, concerns, or changes you want to discuss
- food for your child for 4 to 5 hours
- water bottle
- diapers and wipes (if needed)
- tube feeding supplies or formula (if needed)

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

Your child will also need other tests or procedures to monitor their transplant, like an [electrocardiogram](#) (ECG), [cardiac catheterization](#), [heart biopsy](#), [echocardiogram](#), or [heart MRI](#).

Your child may need to attend physiotherapy and occupational therapy appointments and see other specialists.

Things to remember:

After your child's surgery and when leaving the hospital, **your child should not:**

- lift anything heavier than 10 pounds for 6 weeks after their surgery. This may include milk containers, a heavy backpack, cat or dog food, or another child.
- do any physical activities that put pressure on their chest, like riding a bike or gymnastics, for 6 weeks after surgery.
- immerse their incision (surgery cut) in water (bathing or swimming) until the incision is fully healed.
- immerse their peripherally inserted central catheter (PICC) line in water (if they have one). You can cover and protect it with a waterproof dressing when showering.
- be lifted under their arms for 6 weeks after transplant.



Lifting your child after transplant

Pick your child up under their bum instead of under their arms for 6 weeks after transplant. Lifting them under their arms puts pressure on their chest and incision. Be careful when moving young children in and out of car seats.

Once your child is physically and medically well enough, their care will be managed by the closest pediatric heart centre. The transplant team will share their transplant information with your child's home program.

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

What can help with my child's recovery and overall health?

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



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



- Exercise regularly following the guidelines that your child's physiotherapists and doctors give them.
- 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 child's medical condition or the medicines they take.



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

It is important for your child to drink the amount of fluids each day as recommended by the transplant team.



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



- Take good care of your child's teeth and mouth. Examine their mouth every day, before they brush their 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 their transplant team. Your child will take medicines for at least 6 months after their transplant to help prevent thrush.



- To avoid the risk of infection, do not have any routine dental work done in the first 6 months after transplant. After the first 6 months, continue to see a dentist regularly. Before any major work on your child's teeth or mouth, call their transplant team. If emergency dental work is needed in the first 6 months, your child will need to take an antibiotic medicine before the dental work.



- Keep seeing your child's family doctor, pediatrician, and any other healthcare providers for their general healthcare needs.
- See their eye doctor (optometrist) for routine checkups.
- Buy a medical alert bracelet or necklace made for younger children that says they have had a heart transplant, are immunocompromised (take anti-rejection medicines), and lists any other health conditions they have. You can also put this information on a mobile device in a health app. Talk to the transplant team before buying a bracelet or necklace.
- Tattoos and many piercings are not recommended after a transplant. If your teen still chooses to get a tattoo, talk to the transplant team first to make sure they are being [as safe as possible](#).

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



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

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

Your child may experience new emotions or feelings as they adjust to life after transplant.

You can:

- Use the [coping tips from when they were waiting for their transplant](#).
- Ask their transplant team about being referred to someone to help them 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 988: Canada's Suicide Crisis Helpline any time, day or night.
- Visit [Recovery Alberta](#) for a list of resources that can help your child when they are feeling stressed or having a difficult time.

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

How can my child avoid getting sick after their heart transplant?

After your child's transplant, they have a higher chance of getting an infection.

It is important for you and your child to take steps to protect them, like:

- Wash their hands with soap and water or use hand sanitizer, 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 child's transplant team before getting any immunizations, especially live vaccines.** Encourage family members to keep their immunizations up to date.
- Take good care of your child's teeth and gums and have regular dental exams and cleanings. Talk to your child's transplant team about the need for antibiotics for any dental appointments. Your child should not have any routine dental work done in the first 6 months after their transplant.
- Protect your child 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 their transplant. After that, it is recommended to wear gloves and a mask when digging in the dirt and generating dust.
- Avoid other activities that create a lot of dust.
- Take steps to prevent [sexually transmitted infections](#).

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After your child's transplant, they have a higher chance of getting an infection. It is important for you and your child to take steps to protect them.

- Avoid touching animal waste and cleaning animal cages, fish or turtle tanks, and litter boxes. If your child 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 child's face, nose, and mouth, especially with their mouth. Don't let your pet or other animals lick your child's open wounds. Some pets like birds and lizards should be avoided. Talk to the 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 the 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 your child is 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 child's body
- change in colour, amount, and smell (odour) of your child's urine (pee) or stool (poo)
- burning when your child passes urine (pee)
- open sores or wounds that have drainage
- nausea, vomiting, or diarrhea

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

Call your child's transplant team or pediatric heart transplant physician on call to report signs of infection. The transplant coordinator will give you these numbers before your child leaves the hospital.

If your child has trouble breathing, chest or belly (abdominal) pain, uncontrolled high fever, is not eating or drinking, or has any other severe symptoms, go directly to your nearest emergency department.

What is rejection?

Rejection happens when the transplanted heart is attacked by your child's own immune system and their body tries to fight the new heart.

The best way to prevent rejection is for your child to take their anti-rejection medicines on time (at the same time every day), take the right dose, and complete lab work as scheduled.

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

- fever
- fatigue or weakness
- nausea, vomiting, or diarrhea
- irritability
- racing or fluttering heart (abnormal heart rhythms)

Rejection is often discovered by your child's bloodwork, ECG, or echocardiogram results before any symptoms appear. If the transplant team thinks your child has rejection, they may need a [heart biopsy](#). A biopsy is a procedure, done in the cardiac cath lab, where a needle is used to take a small sample of your child's heart for testing. Your child will be admitted to the hospital for a biopsy and is given medicines to keep them comfortable. If rejection is confirmed or suspected, your child's transplant team may increase the doses of their anti-rejection medicines or give them different medicines.

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

Rejection can happen at any time, but your child is at highest risk in the first year after their transplant. Talk with your child's transplant team if you have any questions or concerns about rejection.



Any time your child is being seen in an emergency room, **always** ask for the transplant team to be consulted.

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

What can we know about the donor?

When your child receives a heart transplant, the heart is given to them without the donor's name, sex, age, location, or any other details. This is to protect information about your child, the donor, and the donor's family.

If you or your child want to write to the donor's family, there is a letter writing process to say thank you. In most cases, 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 child's transplant team.

Medicines after your child's heart transplant

What kind of medicine will my child need to take after their heart transplant?

[Anti-rejection medicines](#) (also called immunosuppression medicines) prevent your child's immune system from attacking their transplanted heart. Anti-rejection medicines include:

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

Your child will need to take anti-rejection medicines every day for the rest of their life.

Not taking these medicines as instructed, or missing doses, can lead to rejection, which can cause the new heart to stop working properly right away and also shorten how long the transplant lasts.

Your child should take these medicines at the same time of day they took them in hospital, unless you have talked with their transplant team about different timing. **Never** stop taking these medicines or change your child's dose without first talking to their transplant team. Always have at least a 2-week supply of medicines and never run out.

When your child takes anti-rejection medicines:

- They will need to get bloodwork done often to monitor their medicine levels.
- Their blood tests must be done **before** they take their anti-rejection medicines.
- Talk with their transplant team before taking any over-the-counter vitamins, medicines, herbal products, supplements, or medicines prescribed by anyone other than their transplant team. Many other medicines can interact with anti-rejection medicines.
- Ask your child's transplant team which medicines they 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 unless discussed with your transplant team.
- Some foods will interact with your child's anti-rejection medicines. Talk to the transplant team to learn more about which foods to avoid.
- Tell your child's pharmacist, dentist, and all other healthcare providers that they are taking anti-rejection medicines.

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Your child will need to take anti-rejection medicines every day for the rest of their life.

- Talk to your child's transplant team about when to take their anti-rejection medicines if they are travelling to different time zones.
- Your child should 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 child's risk of some types of cancer. For more information, talk to the transplant team.

There are other medicines your child might also need to take:

- medicines to protect their 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 them against infection
- water pill (also known as a diuretic) to help their body remove extra fluid
- medicines to keep up with essential nutrients like calcium, magnesium, iron, or vitamin D
- 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, like vitamin D and multivitamins. Talk with your child's transplant team before you give them any over-the-counter vitamins, medicines, herbal products, or supplements.

You are responsible for making sure your child gets and takes their medicines. Talk to their 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 your child forgets to take a dose or vomits after taking a dose
- when and how to order more medicines so your child doesn't run out

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.

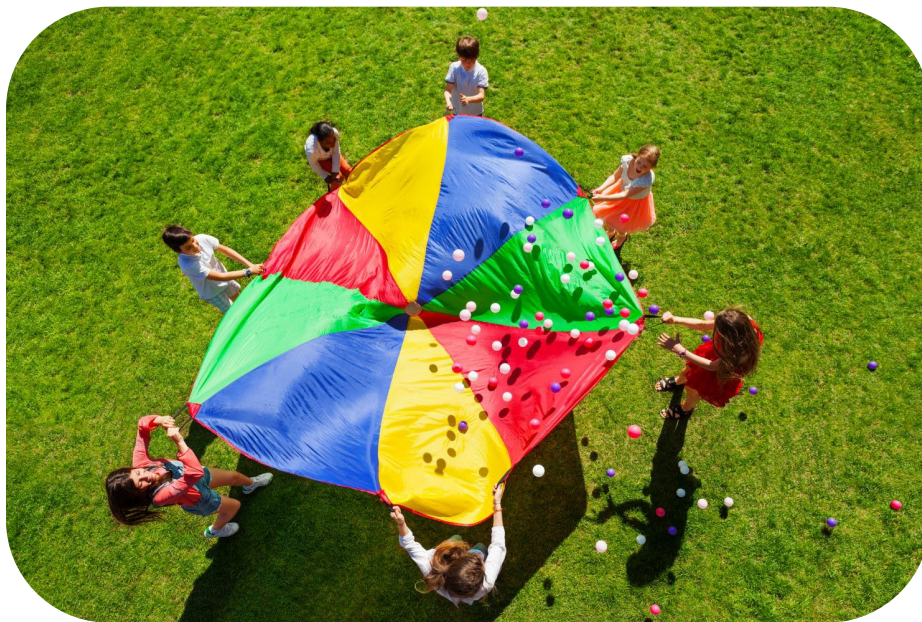
Other medicines your child needs after transplant can be very expensive. Depending on your drug insurance plan, you may have to pay some of the cost on your own. Talk with your child's social worker to make sure you have medicine coverage in place.

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Talk with your child's social worker to make sure you have medicine coverage in place.

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Remember: Your transplant team is here to support you and your child through their transplant journey.



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