GASTROENTEROLOGY
AND CLINICAL NUTRITION

Liver Transplantation

A GUIDE FOR FAMILIES

Liver Transplantation—A Guide for Families
The Royal Children's Hospital Melbourne

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Thomas, Amanda, Anna, Harrison, Morgan, Wade, Veronica, Sarah, Marley and Craig.

The liver transplant service is grateful to Shirley Jacobs, a liver kids mum who helped find the magic in every day.

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Liver transplant overview

Introduction to liver transplantation at The Royal Children's Hospital

The Liver Transplant Program at The Royal Children's Hospital (RCH) in Melbourne, part of the Victorian Liver Transplant Unit (VLTU), provides life-saving liver transplants for children.

This special program has a big mission: to help children from all over Victoria, Tasmania and South Australia who need a liver transplant to survive and live healthy lives.

This guide has been created to give you helpful information about what to expect as you go through the liver transplant journey with your child.

The VLTU provides both adult and child liver transplants and works across two locations: the children's campus at the RCH in Parkville and the adult campus at Austin Health in Heidelberg.

Transplant surgeries for children are done by skilled surgeons from Austin Health at the RCH. Patients are then followed up by Gastroenterologist/Hepatologist for many years after.

By December 2024, The Royal Children's Hospital has performed 260 liver and multi-organ transplants, including:

- 4 combined liver and kidney transplants
- 2 combined liver and pancreas transplants
- 4 liver, pancreas, and intestinal transplants
- 1 isolated intestinal transplant

260

Background

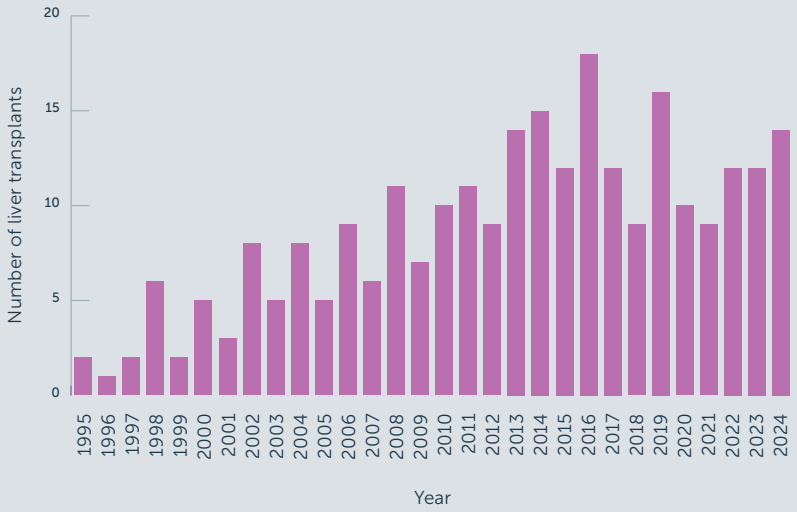
Liver transplants offer a chance at life and new hope to many Australians.

The first successful liver transplant in the world was completed in the United States in 1963, with the first paediatric transplant following in 1967.

Here in Victoria, Austin Health began its liver transplant program in 1988, and in 1995, the first child received a liver transplant at the RCH.

This program has been growing ever since, helping many children who need new, healthy livers to have a second chance at life.

Number of liver transplants per year at The Royal Children's Hospital



When would a transplant help?

A liver transplant is a special surgery that can help children live longer, feel better, and have a good quality of life.

In this surgery, the sick liver is removed and replaced with a healthy liver from another person. This person is usually an organ donor, someone who has died and decided to donate their organs to help others.

A liver transplant might be possible if:

- The disease can be cured or made much better with a transplant, and it will help the person feel healthier and happier
- There are no other serious health problems that could stop someone from surviving the transplant, like active cancer.
- The person will be able to follow the doctor's advice and take care of themselves after the transplant, including in the future.

A liver transplant can be done for different kinds of diseases and conditions. Some diseases might come back after the transplant, or they might not go away completely. That's why it's important for doctors to keep a close watch on patients, and some children may need extra treatments for their condition even after getting a new liver.

RCH patient Harlen *Photo: Herald Sun*

RCH patient Montana *Photo: Herald Sun*

Who can have a liver transplant?

In Australia, the Transplantation Society of Australia and New Zealand (TSANZ) has rules that help decide who is able to receive an organ transplant.

They also guide doctors on how to fairly give donated organs to patients who need them.

To be able to have a transplant, patients must be committed to keeping their body healthy. This means no smoking, drinking alcohol or using illicit drugs. They also need to follow their doctor's advice and take any prescribed medications. These rules help make sure that donated organs go to people who will take good care of them and follow all medical instructions.

This way, organ transplants can be as successful as possible, helping patients live healthier lives.

About the liver

The liver is an important organ that everyone needs to live.

It is in the upper right side of your abdomen, protected by your ribs. It sits below your diaphragm and above your stomach, right kidney, and intestines.

When you're an adult, the liver weighs about 1.5 kilograms.

A healthy liver is dark reddish-brown and shaped like a wedge.

The liver has two main parts, called lobes: the left lobe and the right lobe.

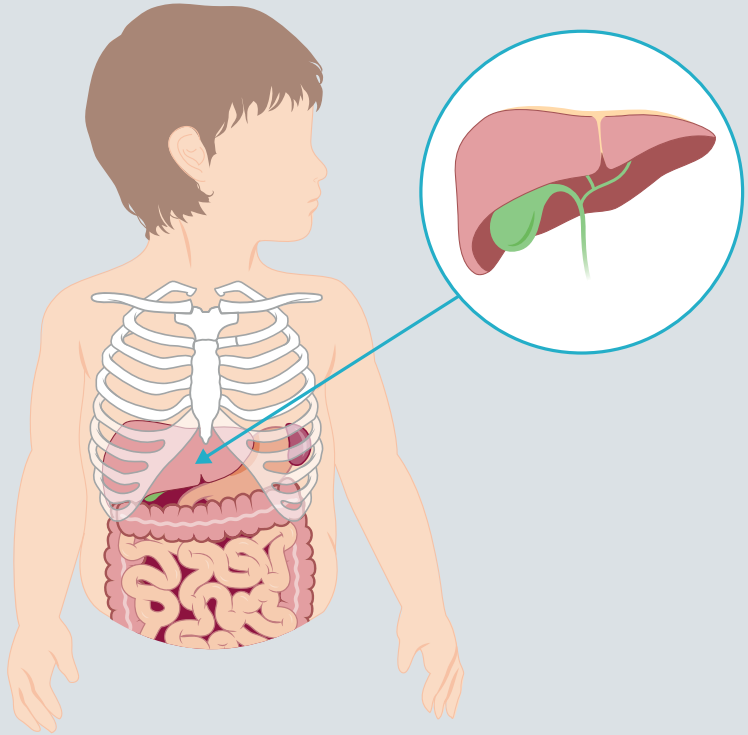


Figure 2. Position of liver in the body

Anatomy of the liver

All parts of the liver have an important job. These parts are:

- **Hepatic artery** Brings oxygen-rich blood to the liver.
- **Portal vein** Brings nutrient-rich blood from the stomach and intestines to the liver to be cleaned.
- **Hepatic vein** Takes the cleaned blood out of the liver.
- **Gall bladder** Stores bile, which helps digest fats.
- **Bile duct** Carries bile from the liver and gall bladder to the intestine.

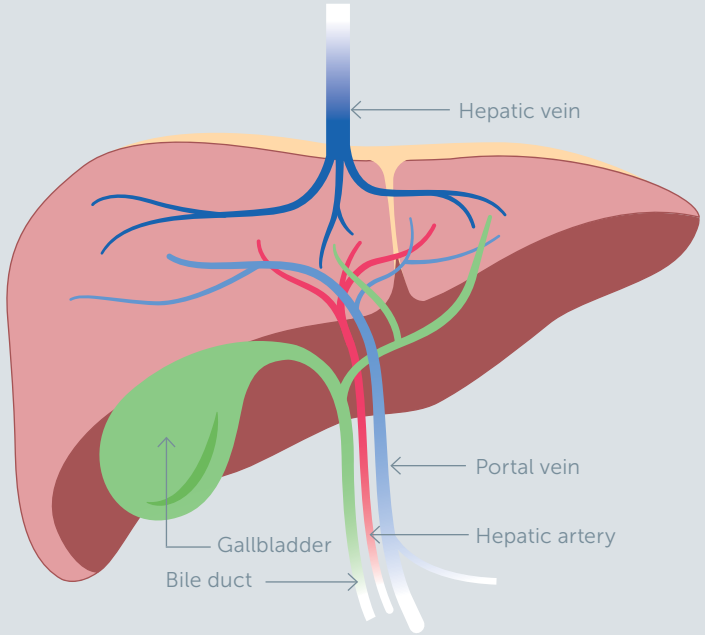


Figure 3. Anatomy of the liver

What does the liver do?

The liver is an important organ that does many jobs to keep us healthy:

- **Makes bile** The liver makes a liquid called bile, which helps break down fats in our food so we can use them for energy. Bile also helps get rid of waste.
- **Makes proteins** The liver makes special proteins that are important for blood, like albumin (which keeps fluid in your blood), and proteins that help stop bleeding when you get a cut.
- **Handles cholesterol and fats** The liver makes cholesterol and helps carry fats through the blood to where they are needed in the body.
- **Stores and balances sugar** The liver stores extra sugar from food as something called glycogen, which can be changed back to sugar when your body needs more energy.
- **Balances protein building blocks** The liver helps balance amino acids, which are the parts of proteins, to make sure your body has what it needs.
- **Reuses iron** The liver breaks down old red blood cells and saves the iron from them to make new red blood cells.
- **Removes harmful substances** The liver helps clean the blood by breaking down harmful things like drugs and alcohol so that they aren't as dangerous.
- **Changes ammonia to urea** The liver changes ammonia, which is a harmful waste from breaking down proteins, into something safer called urea. Urea is then removed from the body in urine.
- **Helps blood clotting** The liver makes things that help your blood clot, which stops you from bleeding too much when you get a cut.
- **Fights infections** The liver helps the body fight infections by making immune substances and getting rid of germs from the blood.
- **Gets rid of bilirubin** Bilirubin is waste made when red blood cells break down. The liver helps get rid of bilirubin. If it doesn't, your skin and eyes can turn yellow, which is called jaundice.

RCH patient Abbey with her mother Shirley

Important blood tests

Liver function
Shows what is happening in the liver and bile ducts.

Urea and electrolytes
Checks the fluid levels in the body and how well the kidneys are working.

Coagulation studies
Measures how long it takes for blood to clot.

Full blood count
Checks for problems and counts different blood cells, like red blood cells, white blood cells, and platelets.

Iron study
Measures how much iron is in the blood and other cells

Liver transplant assessment

What is a transplant assessment?

All children referred for a transplant need an assessment to see if it's the best treatment for them. Sometimes, other treatments like medications or surgeries may be better. Some children have a specific reason a transplant is not right for them. They may be too sick or have a home environment that is not well suited to post transplant care.

The assessment aims to ensure a transplant offers the best chance for a good quality of life. It checks overall health, other conditions, and if the family is ready. This helps decide if and when a transplant is right, if other organs need attention, and how the team and families can prepare.

The transplant plan includes the type of transplant, medicines to prevent infection and rejection, and other important details.

Gastroenterologist George Alex and patient Lola in outpatient clinic

Tests and assessments your child may need

Pathology
- Urine test
- Blood test
- Swabs

Imaging
- X-Ray
- Ultrasound
- Bone density
- CT scan
- Echo (bubble)

Assessments
- Physical
- Lung function
- Oximetry

How long does a transplant assessment take?

The time it takes to finish an assessment depends on a few things, like how quickly the transplant is needed and how long it takes to get test results or do more tests.

An assessment while staying in the hospital (inpatient) takes from a few days to a week.

An assessment with day visits (outpatient) takes from a few weeks to a few months.

Teams involved before, during and after transplant

Gastroenterologist/Hepatologist

The Gastroenterologist or Hepatologist will be the main doctor taking care of you or your child during the transplant journey. They are experts in how the digestive system works. They will check how your child's liver is working and how it affects the rest of your body.

The assessment includes:

- Clinic visits
- Reviewing your child's medical history
- Diagnosing any issues
- Managing symptoms
- Reviewing and ordering blood tests
- Reviewing and prescribing medications
- Physical examination
- Endoscopy
- Liver Doppler ultrasound/Liver biopsy
- Providing a plan of care

Hepatologists Professor Winita Hardikar and Dr Liz Bannister

Liver Transplant Clinical Nurse Consultants Lauren Herd and Alex Hodgson

Liver and Intestinal Transplant Clinical Nurse Consultant (CNC)

The Liver and Intestinal Transplant CNC is an advanced practice nurse who helps patients who need a transplant, they are a central point of contact for parents and the transplant team. Their job is to:

- **Guide and support** They explain what will happen before, during and after the transplant and answer any questions you or your child might have.
- **Coordinate care** They make sure everyone involved in your child's care is working together, including doctors, other nurses, and specialists.
- **Transplant coordination** When an organ is ready and a transplant is planned, the CNC helps organise everything. They tell you when to bring your child to the hospital and give you all the important instructions and information you need.
- **Plan** They help plan the steps before and after the transplant, like tests and follow-up care.
- **Monitor health** They keep track of how your child is doing and make sure everything is going well with treatment.
- **Education** They teach you and your child about the transplant process, how to take care of your child as well as yourself, and what to expect.

In short, they are your guide and helper throughout the transplant journey, making sure your child gets the best care possible.

Nurses

The nurses in Cockatoo (our surgical ward) and Rosella (our Paediatric Intensive Care Unit) know how to care for children with liver disease or who have had a liver transplant.

All the nurses are ready to answer questions or talk about any concerns you have about your child's progress or transplant care.

While your child is in the hospital, the nurses will give you updates about the care plan and how they are doing. They will also work with you to help your child recover quickly and get back home.

Physiotherapists and Occupational therapists

The physiotherapist and occupational therapist are important members of the liver transplant team. Before the transplant, they assess your child's physical development, movement, daily skills and provide strengthening exercises to establish a baseline. After the transplant, they continue to see your child regularly.

Physiotherapists Adrian Whitman and Hannah Marshall

Children with liver disease often have weak muscles and difficulties with daily activities, so the physiotherapist provides exercises to improve strength, while the occupational therapist helps your child develop skills for activities like dressing and playing. They also teach breathing techniques to keep the lungs healthy, such as fun blowing games and sitting up in bed.

The physiotherapist will encourage early movement, like sitting up and walking, while the occupational therapist will support your child in resuming everyday activities. Both will provide exercises or activities to do at home if needed. They will track your child's progress and can arrange further therapy in the community if necessary.

Child life therapist

Child life therapists are trained to help children cope with being in the hospital, going through medical procedures, and continuing to grow and learn. Children can be referred to Child Life Therapy during different stages of their illness, like a clinic visit, hospital stay, or before a transplant.

Therapists provide activities based on the child's condition, interests, and age. They use play to help children express fears and explain medical procedures using dolls. They also teach ways to feel better about treatments.

Speech therapist

Speech therapists help children with talking, eating, and swallowing.

In a liver transplant, they play an important role before and after surgery, assessing language skills and oral motor skills.

If there are delays in any of these areas before transplant or after transplant, the speech therapist can assess your child, to make sure they can eat safely, and that their muscles for chewing and swallowing are strong. They may also help if your child has trouble talking clearly. The speech therapist will guide you on how to practice these skills at home to help your child get better.

Social worker

A social worker is part of the transplant team to support children and families during the transplant process. They provide emotional support through counselling to help families manage the stress and emotions that come before, during, and after a transplant.

The social worker helps parents cope with waiting for a donor organ, the hospital stay, and any changes after the transplant. They also assist with practical issues like travel, places to stay, and financial concerns.

You can meet with the social worker in the clinic or hospital for help with emotional, financial, and practical needs. They are always there to answer questions or concerns.

Dietitian

It's important for us to watch what your child eats. We know that good food:

- Helps the body fight off sickness
- Is important for growing and getting stronger
- Can help your child do better after a liver transplant
- And makes your child feel good overall

Sometimes, children with liver problems have a hard time eating enough. This might be because they need more food than usual, or they don't feel like eating or drinking.

The dietitian will check your child's food and growth. They will give you tips to help your child eat more if needed. You can talk to the dietitian at the Outpatient clinic or when your child is in the hospital, the doctors and CNC's can help to set up an appointment.

Pharmacist

The pharmacist in the ward and outpatient clinic is an important part of the liver transplant team. The pharmacist can talk with you about your child's medicines and answer any questions you have about what the medicines do, when to give them, and the easiest way to give them. Before your child goes home after a transplant, the pharmacist will make a plan that shows all the medicines your child needs and when to give them. This plan will help you manage all the different medicines.

After your child leaves the hospital, most medicines are available from a regular pharmacy, but some medicines are only available from the hospital pharmacy. We will let you know which medications these are after the transplant.

It's important to contact the hospital well before your child's medicine runs out, so you don't run out of any important medication.

Other teams that might be involved in the assessment

- PICU (Paediatric Intensive Care Unit)
- Haematology
- Comfort Kids
- Yalingbu Yirrambo, The Royal Children's Hospital School

RCH dietitians Bianca Sowerby and Sophie King

Teams involved in transplant assessment and testing

Cardiology

The cardiology team checks the health of the heart to make sure it is healthy for the liver transplant surgery and recovery.

The assessment includes:

- A check-up and examination by a cardiologist (a doctor who specialises in the heart)
- An echocardiogram (a heart ultrasound)
- An ECG (a test that measures the heart's electrical activity)
- A Bubble ECHO (a special heart test, but not for all patients)

Respiratory

The respiratory team checks how well the lungs work and how they handle oxygen to make sure there are no problems that could affect the patient during or after the transplant.

The assessment includes:

- A check-up and examination by a Respiratory Physician (a doctor who specialises in lungs)
- Monitoring oxygen levels while sleeping and a finger prick blood test after waking up
- A chest X-ray
- A lung function test (for children over 5 years old)

Anaesthetist

An anaesthetist is a special doctor who makes sure your child stays asleep and feels no pain during the liver transplant surgery.

They will meet you before your child is placed on the waiting list and review all the tests that have been done to plan for the transplant operation.

During the transplant, the anaesthetist continues to monitor your child's sleep, breathing, heart rate, and other important body functions throughout the surgery to keep them safe. After the surgery, they help your child wake up safely and manage any pain. The anaesthetist is there from the beginning to the end of the operation to make sure everything goes smoothly.

Transplant surgeons

The transplant surgeons are the doctors who will do the liver transplant operation, and they meet all patient before they go on the transplant waiting list. As part of the assessment, they will also:

- Do a physical check-up
- Measure the abdomen (belly) and chest
- Look at X-rays and other radiology images
- Make a plan for the surgery
- Talk to you about the risks of the surgery
- Have parents and the child sign a consent form

Nephrology

As part of the assessment process, your child will have several tests to check how well their kidneys are working. If there are any concerns that a liver transplant might affect the kidneys, we will ask a nephrologist (a doctor who specialises in the kidneys) to review your child.
The assessment includes:

- Blood tests
- Kidney ultrasound (usually done at the same time as a liver ultrasound)
- Urine tests
- Glomerular filtration rate test (not for all patients)

Immunisation and infectious diseases

The infectious disease team plays an important role when a child is being considered for a liver transplant. Their job is to check if the child has any infections that could make the transplant risky. They look for signs of infections the child might have had in the past or might have now, which could affect how well the transplant will go.

They also make sure the child is up to date on vaccines to prevent future infections after the transplant. This helps keep the child as healthy as possible before, during, and after the surgery. The assessment includes:

- Immunisation history
- Blood tests
- Swabs of nose, armpits, groin and bottom
- Urine and stool samples
- Family immunisation assessment
- Travel questionnaire

Key points about immunisations

- Immunisations are very important to keep children healthy after a liver transplant.
- All immunisations on the National Immunisation Program schedule should be given before and after the transplant.
- Children who need, or have had a transplant, will also need extra immunisations, like the one for Meningococcal B.
- It's important for children to get the flu vaccine every year.
- Immunisations for measles, mumps, rubella, and chickenpox can't be given after a liver transplant, so these need to be done beforehand.
- Everyone in the household should be fully vaccinated, and it's strongly recommended they get the flu vaccine every year.

Summary of assessment

After all the appointments and tests are done, the results are given to the liver transplant team. Together, they check:

- If your child's current health can be improved with special treatment and if so, they make a detailed plan. This will mean your child will be better prepared for transplant or may be able to delay the need for transplant if they improve significantly.
- If any of the test results need to be looked at more closely.
- If your child is a good match for a transplant.
- If your child is ready for a transplant, and when they should be put on the waiting list.

If your child is not ready for a transplant, your doctor will meet with you to explain why. There might be some things to work on before they can be ready for a transplant, or other treatments to try first.

Liver transplant waiting list

Activation on the waiting list

If the child is suitable for a liver transplant and you and your child's doctors agree to proceed, your child will be placed on the active transplant list. To be put on the active transplant list, or "activation", means that your child has been approved to receive a transplant, and you can be called to come in for a transplant at any time.

While on the waitlist

The waiting time for a transplant is unpredictable and can be anywhere from a few days to many months, depending on your child's size, health, blood type, and immune system. Waiting can be difficult for families, as you wait for a phone call with news of a possible liver transplant. During this time, families must stay within a few hours of the hospital and always be reachable by phone. Please let us know if you will be away from home, or hard to contact.

Your child will be checked often during this time, and they may get sicker and need more help and care from you. There might be more hospital visits, and some children may need to stay in the hospital while waiting for the transplant. If your child becomes too sick while on the waiting list, they might be put on hold until they get better, or they might not be able to have a transplant.

Your child's doctors, the liver transplant nurse, the social worker, and the transplant team are all here to talk to you about your concerns and to help and support you during this time.

"The hardest part is not the transplant, its that space of time between being listed and receiving the transplant."

– Sarah Dowell, mother of RCH patient, Marley

Unwell on the waiting list

If your child is sick, you need to let us know so we can make the best choices for their safety with the transplant.

For some infections, like the flu, COVID-19, or a bacterial infection, we may need to put your child on hold until they are better because it may not be safe for them to have surgery while they are sick, as it could put extra stress on their body.

The medicine they need after the transplant could make the infection worse, and they could get very sick.

RCH patient Harry, with his mother Anna

Organ donation

Organs for transplant

Organs for transplant come from people who have had serious brain injuries or have died in the hospital's Intensive Care Unit (ICU) due to a severe accident or illness. There are two types of organ donors —Brain Dead Donors (BD) and Donation after Cardiac Death Donors (DCD).

Brain dead donors

A Brain Dead (BD) donor is someone who has had serious brain damage that can't be fixed. They can't breathe on their own or wake up. Blood has stopped flowing to their brain, and their heart will soon stop beating. Machines are needed to keep them breathing. Special tests are used to show that a person is brain dead, and there are also laws that explain when and how doctors can say that someone is brain dead.

Donation after Circulatory Death (DCD) donors

A DCD donor is someone who donates their organs after their heart has stopped beating. This is different from someone who has BD, where the brain stops working but the heart is still beating with help from machines.

The donation can only happen if the persons heart stops within a certain time frame. If they don't pass away in the time frame, it means the organs will not be suitable to be used for transplant.

Living related donors

Living related donation is when part of a healthy person's liver is given to someone with liver disease. Deciding to be a living donor is a very big decision because removing part of a liver is a major surgery.

Before someone can be a donor, doctors do a lot of tests to make sure the person is healthy, that their liver is a good match for the person who needs it, and that they understand their choice. If a family considers this option, the transplant team will check if a parent can donate to their child. For more information, please talk to your child's doctor.

How are organ donors assessed?

The Organ Donation Nurse Consultant (ODNC) talks with the family of the person who might be a donor and asks many questions about the donor's medical and social history. They also arrange important tests to make sure the organs are healthy and safe for donation. This is done to make sure the organs can be used without passing on any infections or diseases to the person receiving them. Other organs that might also be donated include the heart, heart valves, lungs, pancreas, skin, bones, kidneys, and corneas. The ODNC organises the surgery to remove the liver and any other organs for transplant.

How do organs get to the hospital?

After the liver is taken from the donor, it is kept in a special liquid to keep it fresh and then placed on ice. The liver needs to be transplanted within 10 to 12 hours. The Liver CNC stays in touch with the person transporting the liver to make sure it is safe. When the courier arrives at the hospital the operating theatre technologist picks up the liver and takes it to the operating room.

Privacy and social media

The *Human Tissue Act 1982* makes sure organ donor and recipient identities are kept private. However, recipients or their families often write a thank-you letter to the donor family without sharing names. This letter is sent to the donor family through the Liver and Intestinal Transplant CNC and the ODNC. Here are some important things to remember:

- You and the donor family's identity will stay anonymous during and after the transplant.
- It's recommended not to share dates and times of the transplant on social media or with the news.
- If you want to share your story with the media after the transplant, it's best to contact the RCH Communications Team to help protect everyone's privacy.

Communicating with donor family

After a liver transplant, the person who received the transplant and the family of the donor can send letters, cards, or drawings to each other.

These messages need to follow special rules in the *Human Tissue Act 1982* and DonateLife Guidelines to make sure they are respectful and keep everyone's privacy safe. This means personal details like names, addresses, schools, or anything else that could identify the recipient or donor should not be included.

Some families worry about not being able to properly thank the donor family. However, most donor families are happy to hear from the people who received the transplant.

Focus on sharing how the transplant has made life better for your child and family. For example, you could talk about what you hoped for before the transplant and how things have changed since. What new things can your child do now that they couldn't do before, such as going on trips or holidays.

After the transplant, you will receive more information about how to write to the donor family. The liver transplant team can also help by checking your messages and making suggestions, if needed.

"Dear Donor Family,

It is with deep sympathy, love, and gratefulness that we send you this letter. Our grieving and worry only ended because of your gift you so courageously and selflessly gave in a time of great sorrow. We want so much to say thank you for the precious gift you gave us...

After a shaky start with a few complications our daughter is now doing so well.

The last four years have seen her in such poor health, missing school, friends, socials, and extracurricular activities.

The last four months before her transplant were spent mostly as an inpatient at hospital.

Now just a few months later, she is having friends over, going out with friends, shopping, and to the movies and preparing to return to school in the new term.

You have given me the hope and belief that she can be more than just a sick child."

Example of a letter to a donor family

Liver transplant surgery

When a donor liver becomes available

A Liver and Intestinal Transplant CNC from the RCH or Austin Hospital coordinate the transplant, they are main point of contact for the patient and hospital staff regarding information about the planned transplant.

When a suitable liver is available, the CNC will call you to help arrange transport to the hospital. This could be by car, taxi, or even plane if needed. They will ask you some questions about the health of your child, and tell you if your child needs to fast (stop eating or drinking or both) or stop taking any medications before coming in. It's a good idea to keep a bag packed with everything you and your child will need for the hospital stay. Usually, there are several hours between getting the call about a liver and the actual transplant, so that we can make sure your child is prepared properly.

Preparation for transplant

The CNC will let you know when to come into hospital and when your child needs to start the fasting ahead of the surgery.

Travel to the RCH	Emergency	Cockatoo	Operating Theatre
Bring all your medications with you and tell the CNC when you expect to arrive.	Chest X-Ray	• IV access • Blood test • Swabs • Wash • Cream applied • Doctor review	Liver transplant surgery

Cancelled transplant

Sometimes, we need to cancel a transplant at the last minute if the liver isn't right for your child.

The donor liver might not be right for your child for different reasons, like:

- It doesn't look healthy—it could be fatty, swollen, or the wrong colour.
- It can't be made smaller to fit your child because of where the blood vessels are.
- It might not have the correct texture or feel.
- It might not have good blood flow.

We understand this can be very disappointing and frustrating, but it's important that your child gets the best liver for them.

RCH patient Harlen in theatre before transplant *Photo: Herald Sun*

Types of donor livers

The kind of liver your child gets will depend on a few things:

- Your child's size
- The size of the donor (the person giving the liver)
- The shape and structure of the donor liver

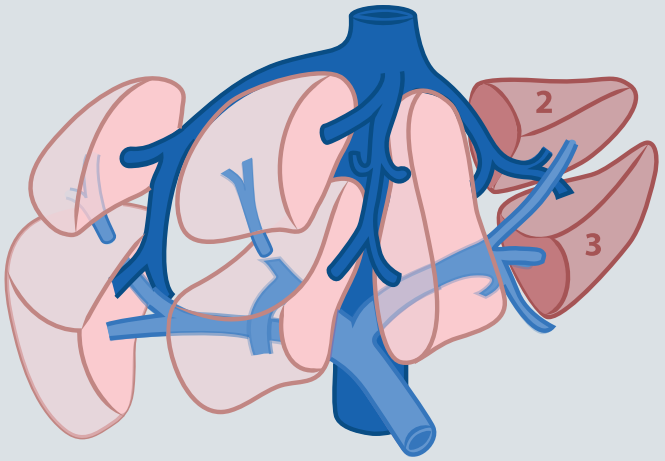


Figure 4. Liver segments. Segments 2 and 3 are used for a split liver transplant.

During the transplant surgery, your child's liver will be taken out completely. If they have a gall bladder, it will also be removed. The donor liver needs to fit in the space where your child's liver used to be. Choosing the right size is important to make sure the donor liver works well after the surgeons attach it to your child.

Whole donor liver

If the organ donor is about the same size as your child, we can use the whole donor liver without needing to make it smaller.

Split donor liver

If the donor liver is too big for your child, the transplant team might decide to split it into two parts. One part will be given to your child, and the other part will be given to another person waiting for a liver transplant.

If the donor is a living relative, it is a similar procedure, except the donor would keep the other part of the liver.

Reduced donor liver

If the donor liver is too big, can't be split into two equal parts, or if part of it is damaged, your child might get a smaller part of the liver, and the rest won't be used. This is like a split liver transplant, but only one person gets the donor liver.

RCH Patient Jake, with his mother Claire, who donated part of her liver to him

Transplant operation

When the transplant is ready to happen, your child will be taken to the operating room in their bed or cot. You might be able to stay with your child until they are given the medicine that makes them fall asleep. This might happen in a small room or in the operating room. After they are asleep, someone will walk you out. Usually, after your child is asleep, the doctors will put in all the tubes and devices they need during the surgery.

Timings

The anaesthetic and operation together usually take between 10-12 hours and during that time, your child will be cared for by a highly skilled team of surgeons, anaesthetists, nurses and technical staff.

Going to sleep	Anaesthetic	Transplant operation
15 minutes	**1-2 hours**	**6-10 hours**
One parent is able to go with the child to the operating theatre where the child will go to sleep. This may be in a small room next to the theatre, or in the operating theatre itself.	• Insert breathing tube • Insert IV lines and urine catheter • Give medications	• Remove child's own liver • Donor liver inserted and connected • Drain inserted and belly closed • Liver ultrasound

What happens during the operation?

There are many steps during a liver transplant to help make sure it works:

1. Open the belly and get the liver ready to be taken out.
2. Wait for the donor liver to arrive, check it, and get it ready for the child.
3. Clamp and cut the veins, artery, and bile duct.
4. Take out the liver from the belly.
5. Put the new liver in the belly and sew the veins together.
6. Remove the clamps and let the blood flow through the new liver.
7. Sew the arteries together and remove the clamp.
8. Connect the donor's bile duct to the child's bile duct or bowel.
9. Close the belly.
10. Do a liver ultrasound to make sure everything is working well after the surgery.

Liver arriving in theatre *Photo: Herald Sun*

Connecting the bile ducts

There are two ways the transplant surgeons can connect the donor's bile duct to your child:

- **Duct-to-duct** The donor's bile duct is connected directly to your child's bile duct. This is more common when the donor liver is a full liver and matches your child's size.
- **Roux en Y** (said "roo in why") This is more common with split or smaller donor livers because the shape is a bit different. The surgeons focus on connecting the liver to your child's blood vessels first. If your child's bile duct doesn't reach the donor bile duct, the surgeons take a piece of bowel and connect it to the donor's bile duct instead.

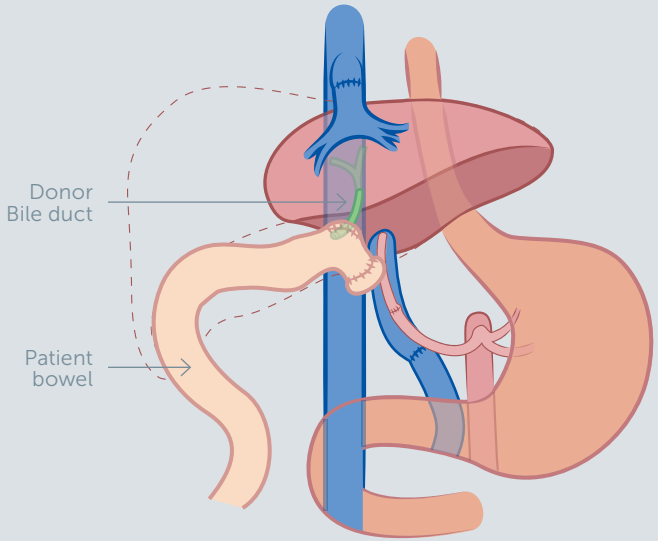


Figure 5. Biliary Anastomosis—Roux en Y

While parents and carers are waiting

Once your child's operation starts, you can go back to the ward to get their things. You can stay at the hospital to wait or go home if it's close and you'll be more comfortable. The transplant nurse can help you find a place to stay if you want to stay near the hospital. Please let us know if you would like the Chaplain to visit while you wait for the transplant to finish.

Once the transplant is finished, your child will be moved to Rosella, our recovery ward, where they will stay for the next few days. It might take an hour or two for your child to be ready for you to visit.

Communication with the transplant team

The Liver and Intestinal Transplant CNC will provide you with progress reports during the operation, inform you when the surgery is scheduled to finish, and when the transplant surgeon will be available to speak with you. They will call you every few hours to tell you how things are going.

Risks during surgery

During a liver transplant surgery, there are specific risks that can affect a child's chances of survival.

One major risk is bleeding, as the liver has many blood vessels, and surgeons must carefully remove the damaged liver and attach the new one. If too much blood is lost during the operation, it can be dangerous.

Another risk is that the new liver may not start working right away, a condition called "primary non-function," which can be life-threatening. Blood clots can also form in the veins connected to the liver, blocking blood flow and causing serious complications.

In addition to these surgical risks, anaesthesia also carries its own dangers, especially in children. Some children may have allergic reactions to the anaesthesia, or they could experience breathing problems during the surgery.

The doctors monitor the child closely to manage these risks, but because of the complexity of the operation, there are still chances that things could go wrong.

Blood products

Your child will require multiple blood products during and after transplant to:

- Prevent bleeding
- Prevent blood clots forming
- Maintain the bodies normal circulating blood components that the liver would normally do

Blood products can include packed cells, plasma, platelets, albumin, or antithrombin.

During surgery, your child may lose a lot of blood. This blood is collected and "recycled" using a cell saver.

What to expect in hospital after the transplant

Admission to Paediatric Intensive Care Unit (Rosella)

Right after a transplant, children stay in the Paediatric Intensive Care Unit (PICU) Rosella ward because they need special care. In Rosella, each child has their own room and nurse, just for them.

When your child moves to Rosella, it may be confronting to see them at first.

After a big surgery, they may have many tubes, drains, and machines attached and their face might be swollen.

If your child needs help to breathe with a machine, they will be given medicine to keep them calm and comfortable, which also helps with any pain. This medicine is used as long as needed.

While in Rosella, your child will have many tests and procedures, and their vital signs (like heart rate, breathing, and blood pressure) will be watched closely. These tests and checks are normal and help the doctors and nurses see how your child is doing after surgery. The team will explain these procedures and how your child is recovering.

RCH patient Harlen *Photo: Herald Sun*

RCH patient Montana *Photo: Herald Sun*

Visiting

Parents can visit or call the PICU at any time, but they cannot stay or sleep overnight. Other family members can visit during the day. Only two visitors are allowed at a time so that the doctors and nurses can care for your child. It's very important to wash hands well before visiting to help prevent infections. Visitors who are sick or have been around someone with an infection are asked not to visit.

Discharge from Rosella

Children are moved from Rosella to Cockatoo ward when they can breathe on their own, their new liver is working well, and the doctors feel they are stable. This might happen after a few days, but sometimes it can take weeks.

Before your child moves to Cockatoo, some tubes and lines will have been taken out but a few might still be needed. These could include several IV lines, a Jackson Pratt drain tube, a naso-gastric tube, and sometimes a catheter or oxygen.

Moving from Rosella can be unsettling and families may feel a mix of emotions when it's time to leave. However, the nurses on Cockatoo are very experienced in caring for children after a liver transplant.

Admission to Cockatoo

Cockatoo is a 30-bed ward that cares for children from infants to teenagers. The nurses and other staff here take care of patients with different health issues, including brain and nerve conditions, hormone problems, and complex stomach and liver conditions. The team includes nurses, ward clerks, and patient assistants.

On Cockatoo, your child's temperature, pulse, breathing, blood pressure, and oxygen levels will still be checked, but not as often as in Rosella. Blood will be taken twice a day, or sometimes more often, and samples of urine and other fluids will also be needed. Other tests and X-rays might also be done as your child recovers. These checks help to see how well the new liver is working and to catch any infections, rejection, or other problems. The areas with drain tubes will be cleaned and checked every day, but the dressing over the surgery line will be left alone for longer.

The time it takes for each child to recover and go home can be different. Some children stay as short as three weeks, while others may need to stay for some months.

RCH patient Thomas taking his first steps post transplant with the Physiotherapists

Complications after surgery

During and immediately after liver transplant

Liver graft dysfunction

There are two types of liver function problems that can happen during, or right after a liver transplant.

Primary graft non-function (when the liver doesn't work)	**Poor graft function** (when the liver is damaged but still works a little)
• Liver cells start to die. • The person may go into a coma, have problems with the heart and blood vessels, experience bleeding, infections, or kidney failure. • They need an urgent new liver transplant to survive—this is called Category 1. • They might need a machine to clean their blood.	• Liver cells are injured. • Many people need a machine to clean their blood. • They might slowly get better but could have other problems, like infections or needing a long hospital stay. In the long term, they might have scarring in the liver or bile ducts. • They may need another transplant soon, or possibly many years later.

Bleeding

The liver cells make special substances that help to manage blood clotting. After a liver transplant, it might take a few days to weeks for these processes to work properly.

There's a careful balance between stopping bleeding and preventing clots after a transplant. The blood needs to be thin enough to flow through the new blood vessels, which might be swollen for a few days, but also thick enough to avoid too much bleeding.

During a liver transplant:

- Problems can happen due to how the new liver is working, past surgeries, or high blood pressure in the portal vein.
- A large amount of blood transfusion may be needed.

After a liver transplant:

- There can be leaks where the vessels were connected (called the anastomosis).
- Bleeding can also happen from the cut areas of the liver.

Thrombosis (blood clots)

Clots can form in the new blood vessel joins (called anastomoses) at any time after a liver transplant.

Early Thrombosis (clots forming soon after transplant):

- If found during the transplant surgery:
  - The surgeon might need to remove the clots and re-do the blood vessel joins.
  - New blood vessels might need to be created (this is called grafting).
- If found in the first week or two after transplant:
  - They might need another surgery to remove the clot (a thrombectomy).
  - They might need medicine to thin the blood (anticoagulation).
  - This could lead to liver problems, like the liver not working well or failing.

Late Thrombosis (clots forming later):

This can happen at any time after the transplant, even months or a year later.

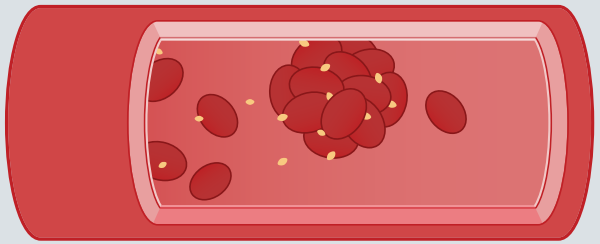


Figure 6. Thrombosis (blood clot) forming

Infection

Line infections

The most common infections in children after a transplant are bacterial infections. These often come from central lines (tubes) that are put in during the transplant surgery. We keep these lines only as long as needed to give important medicines. If there is an infection, it can be found by testing a blood sample from the line.

Wound infections

Wound infections can cause swelling, redness, tenderness, and oozing or drainage from the infected area. Other signs of infection include feeling very tired, fever, and pain around the wound. Common places for these infections are the main surgical wound or the wound drain sites. A swab can help identify the bacteria causing the infection so the right antibiotics can be given.

Chest infections

Chest infections can be due to many different bacterial and fungal infections. Symptoms may include a dry or productive cough (coughing up phlegm), fever and rapid rate of breathing. A chest X-ray may help to confirm the diagnosis. Antibiotics or antifungal medicines will be used to treat the infection.

Bile leak

What is a bile leak?

A bile leak happens when bile leaks from:

- The new join where the bile duct from the new liver is connected to the patient's bowel or their own bile duct.
- The cut edge of the liver.

How is it managed?

- Sometimes, the leak gets better on its own after a few days.
- The child may need to stop eating and take antibiotics.
- They might need another surgery to fix the leak.

During the transplant, a drain is usually placed along the cut edge of the liver to remove any bile that may leak. This drain is usually removed within the first week. As long as the bile doesn't collect in the belly, the child should stay well. Bile leaks often heal over time but may need extra treatments if they don't.

Bowel complications

After a liver transplant, some children may have problems with their bowels, like bowel obstruction or bowel perforation.

Bowel perforation is when there is a hole in the intestines, allowing contents to leak out, which can lead to a serious infection in the belly.

Bowel obstruction is when the intestines get blocked, which can cause belly pain, swelling, and vomiting because food and liquid can't move through properly.

Both of these problems are emergencies and might need surgery to fix. Doctors watch for these complications closely to help the child recover safely.

Kidney injury

After a liver transplant, some children can have kidney problems, called kidney injury.

This happens when the kidneys don't work as well, which can cause a buildup of waste and extra fluid in the body. Kidney injury may happen because of the medicines needed after the transplant or because of changes in blood flow during surgery.

Symptoms might include less urine, swelling, and feeling tired. Sometimes, the child might need special medicines or treatments like dialysis to help the kidneys work.

Doctors watch for kidney problems closely to keep the child healthy and help the kidneys recover.

Rejection

Rejection happens when your body's immune system starts to "attack" your new liver. Your immune system knows the liver came from another person and thinks it doesn't belong. Medicine is used to settle your immune system so it won't attack the liver. Rejection can still happen even if you're taking the right amount of medicine.

There are two types of rejection, acute and chronic:

	Acute rejection	Chronic rejection
Overview	• Can start within the first five to ten days after the transplant. • It is common, happening at least once in about eight out of 10 patients. • More likely in the first one to three months but can happen anytime, even years later. • High doses of immune suppressing medicine are given during and after the transplant to help prevent rejection. • Three types of immune suppressing medicines are used because the risk of rejection is higher at this time.	• Can start a few months or even years after the transplant. • It can happen at the same time as acute rejection. • It is uncommon.
How do you know if there is rejection?	• Liver tests may suddenly show abnormal results that don't improve. • A liver biopsy is used to find out if rejection is happening and to see how severe it is (mild, moderate, or severe).	• Liver tests become abnormal and don't improve. • A liver biopsy is used to diagnose it.
What is the treatment?	• Extra or different immune suppressing medicine may be given until the rejection settles. • IV medicine might be needed in the hospital. • The liver will be closely watched until tests return to normal.	• Extra or different immune suppressing medicine may be given until it settles. • Close monitoring is needed until liver tests return to normal.
Why does it happen?	• Rejection is related to the immune system. • It can happen if there isn't enough immune suppressing medicine, or sometimes after an infection or for unknown reasons.	Chronic rejection is related to the immune system but is different from acute rejection.
Is it serious? What does this mean in the long-term?	• One episode of rejection does not mean you need another transplant. • However, having several severe episodes can increase the chance of chronic rejection. • Rarely, acute rejection might cause the liver to fail, needing another transplant.	If it doesn't respond to a change in immune suppressing medicine, it can lead to liver damage over time and may require another transplant.

Long term complications

Stenosis (narrowing) of blood vessels and bile ducts

A stenosis is when a blood vessel or a tube in the body gets narrower than it should be. This can make it hard for blood or other fluids to flow through easily. In the body, a stenosis can cause problems because things can't move through the narrowed area as they should.

Blood vessels

A stenosis in the blood vessels usually happens where vessels are joined together, and this join is called an anastomosis. When the area heals, a scar forms as a natural part of healing. Sometimes, this scar pulls on the tissue around it, making a small ring that blocks the blood flow.

Diagnosis and treatment:

- Narrowing of the vessels can be found through changes in liver function tests and by using imaging, like a liver ultrasound or a CT scan.
- A procedure can gently stretch the inside of the blood vessel where it's narrowed, using a small tube called a catheter "and a balloon". This procedure is called an Angioplasty (stretch of artery) or Venoplasty (stretch of vein). For more information please see section 10.

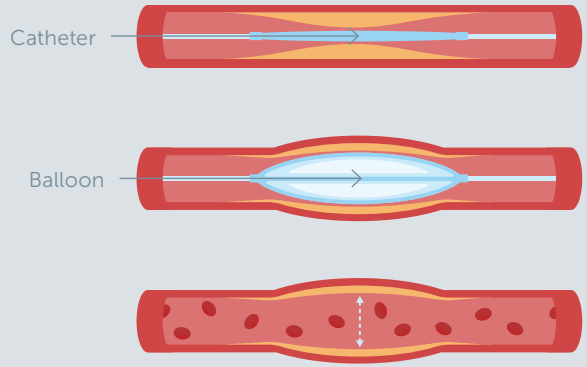


Figure 7. Stretching of blood vessel (plasty)

Bile ducts

Around four out of 10 patients after a transplant have some kind of bile duct problem, which is unfortunately common.

Examples of known risks include:

- The transplant liver being stored on ice before surgery
- The type of transplant, like a DCD or split/reduced liver.
- Problems with the hepatic artery, like narrowing (stenosis) or clots (thrombosis), which can reduce blood flow to the bile ducts and cause damage.
- Issues related to the immune system.

There are two kinds of bile duct narrowing that can happen after transplant:

Stricture This is a narrowing of the bile ducts inside the liver, caused by damage to the lining of the bile duct walls. This can happen if blood flow changes.

Stenosis This is a narrowing at the new join (anastomosis) where the bile duct from the transplanted liver connects to the patient's own bile duct or bowel.

Diagnosis and treatment:

- Narrowing of the bile ducts can be found through changes in liver function tests and by using imaging, like a liver ultrasound or MRI cholangiogram.
- If there is narrowing at the anastomosis, a procedure called a percutaneous cholangiogram may be done to help stretch the narrowed area (this is called dilatation).

Abdominal adhesions

After a liver transplant, some children may develop abdominal adhesions, which are bands of scar tissue that can form inside the belly. These adhesions can make parts of the intestines or other organs stick together. This might cause problems like belly pain or even blockages in the intestines, making it hard for food and poo to pass through. Sometimes, adhesions don't cause any issues, but if they do, surgery might be needed to remove the adhesions to help your child feel better.

Infection

Taking anti-rejection medicine weakens your child's immune system, making it harder to fight infections. Transplant patients commonly get bacterial, viral, or fungal infections, so it's best to avoid sick people, especially in the first three to six months after transplant, and get a yearly flu shot with your family.

Your child is also at risk for viruses like Epstein-Barr Virus (EBV) and Cytomegalovirus (CMV). CMV is usually harmless, but it can become active in people with weak immune systems, especially in the first six to 12 weeks after a transplant or after treating rejection. Watch for symptoms like a high fever or flu-like feeling and tell your transplant team. If needed, you'll receive antiviral treatment.

Other viruses, like Herpes Simplex (HSV) causing cold sores and Varicella Zoster (VZV) causing chickenpox, can stay quiet in the body but might become active after transplant. If this happens, your doctor will give you antiviral medicine as a cream, pills, or through IV.

High blood pressure

High blood pressure (hypertension) is very common after a transplant, partly because of anti-rejection medicine. It's important to look for and treat high blood pressure early to prevent long-term problems with blood vessels. Your doctor will check your child's blood pressure at each visit.

Sometimes, high blood pressure is hard to control and may need several different medicines. Some blood pressure medicines can affect your anti-rejection drugs, so always check with your transplant team or doctor before starting them.

Impaired kidney function

Some of your child's anti-rejection medicines (like tacrolimus) can affect the kidneys, so regular blood tests will help check how well their kidneys are working (by testing things like urea, creatinine, and electrolytes). If your child already has some kidney problems, the transplant team will adjust their medicines to protect their kidneys as much as possible.

Other medicines can raise tacrolimus levels and make kidney problems worse. It's important that your child doesn't take any non-prescribed health products or herbal remedies without checking with the transplant doctor first.

Keeping your child well-hydrated is also very important, especially in hot weather. If they have diarrhoea or vomiting, seek medical advice, as dehydration can make tacrolimus levels rise in the blood and increase the risk of kidney issues.

If your child has high potassium levels, talk to your transplant nurse about which foods to avoid.

Increased cholesterol

High cholesterol (hyperlipidemia) is a rare problem for children after a liver transplant and is different from high cholesterol in adults. It's mostly caused by anti-rejection medicine and levels are checked regularly. To help keep cholesterol at a healthy level, children should eat a balanced diet and get regular exercise, as their doctor suggests. A dietitian can help with choosing healthy foods.

Diabetes

After a transplant, some children may develop diabetes, which means having high blood sugar levels. This is mostly due to the anti-rejection medicines and is more common after being treated for an episode of rejection.

Your doctor will check the blood sugar levels often, especially in the first few months. If your child's blood sugar stays high, they may need help from a dietitian and might need medicine to lower it. Diabetes medicine can be tablets, but sometimes insulin shots are needed. If your child already uses insulin, their dose might need to change regularly.

Metabolic bone disease

Bone thickness (or density) can decrease in the first three months after a transplant because of the high doses of anti-rejection medicine. As the medicine doses are lowered over the first year, bone density should get closer to normal levels.

If your child is taking prednisolone for a long time, their bone density may be checked with a Dexa scan (like an X-ray but with less radiation) to see how strong the bones are. The transplant doctor will tell you how often your child needs this scan. If bone thinning (osteopenia) continues, your doctor might lower or stop prednisolone or give medicine to help strengthen your child's bones.

Nerve (neurologic disorders)

Many patients have some nerve or brain-related issues after their transplant, especially early on. Common symptoms are headaches, shaky hands (tremor), pain in the arms or legs, numbness or tingling in the feet, and extra sensitivity in the skin or hair. These symptoms are often caused by the levels of medicine in your child's body. Talk to your doctor or CNC if your child has these symptoms. They usually get better when the medicine is adjusted.

Bone marrow

After the transplant, your child might have a low red blood cell count (anaemia), a low white blood cell count (leukopenia), or a low platelet count (thrombocytopenia). This can happen because of their illness before the transplant or some of the transplant medicines. A low platelet count can also be caused by a virus, especially Cytomegalovirus (CMV). Your doctor will check the blood cells with regular blood tests and can recommend the best treatments if needed.

Cancer

Patients who take anti-rejection medicines are at an increased risk of developing skin cancers (most commonly) or malignant disease such as lymphoma and solid organ tumours.

Post transplant Lymphoproliferative disease (PTLD)

- A rare disease that can happen after a liver transplant in children, often due to the effects of anti-rejection medicines.
- These medicines weaken the immune system to prevent rejection of the liver but can also cause white blood cells called lymphocytes to grow out of control.
- PTLD can range from a harmless overgrowth of these cells to a serious type of lymph node cancer.
- If you notice any large swelling in your child's neck, armpits, or groin area, tell your doctors right away.
- The oncology team may also check your child to help manage and treat PTLD. Treatment can include antibody therapy and chemotherapy.

Skin cancer

- All transplant patients need to be extra careful about checking their skin for any unusual spots or marks.
- Some types of spots to look out for include sun spots (solar keratoses), squamous cell carcinoma (SCC), and basal cell carcinoma (BCC).
- If a doctor removes a spot that might be skin cancer, they can test it to find out what kind it is and if it has been completely taken out.
- In transplant patients, cancers can sometimes spread quickly to other parts of the body, but regular skin checks can help prevent this.

Other cancers

- Men over 18 should remember to check their testicles every month.
- Women over 25 should have a cervical screening test every five years.

Any of these changes should be reported to a doctor right away:

- bleeding from the bowel
- lumps in the breast or testicles
- unusual or changing spots on the skin

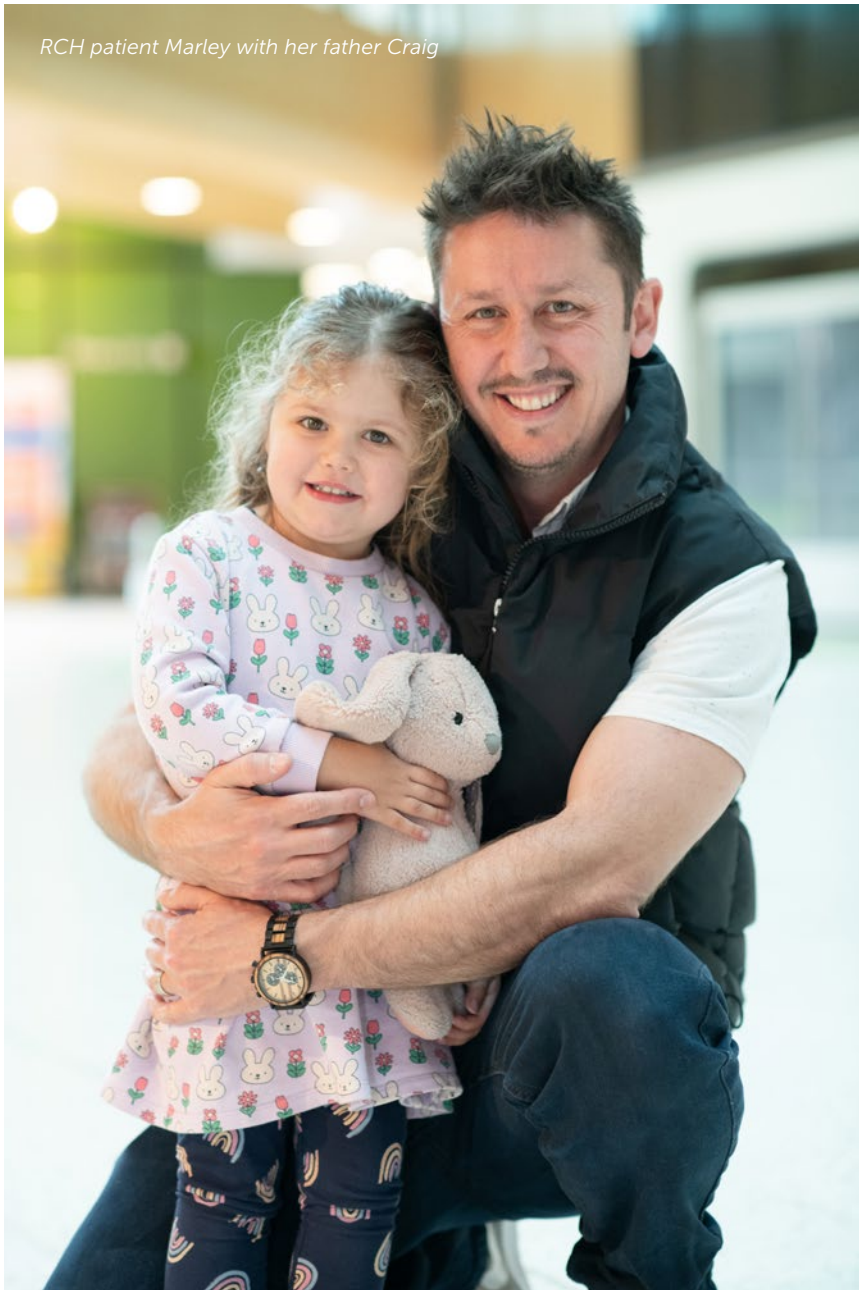
Low magnesium

Magnesium is a mineral that helps with muscles, nerves, bones, energy, heart rhythm, blood sugar, and blood pressure. The medicine tacrolimus, used after a transplant, can cause more magnesium to be lost from the kidneys. Low magnesium can cause muscle aches, irritability, and, in severe cases, an irregular heartbeat. Most people taking tacrolimus will need magnesium supplements to keep levels normal.

Ways to increase magnesium:

1. **Food** Some foods high in magnesium include leafy greens, soybeans, nuts, and fruits.
2. **Through skin** Magnesium can be absorbed through the skin using:
   - Epsom salts. Add 1–1½ cups to a warm bath, then add cold water. Available at supermarkets and pharmacies.
   - Magnesium salt flakes. Similar to Epsom Salts but with more magnesium, found in health stores.
   - Magnesium oil. Rub on skin after a bath. Do a patch test first, as some may be sensitive.

For best results, use salt flakes in the bath daily. Avoid eyes and rinse hair with fresh water.



RCH patient Marley with her father Craig

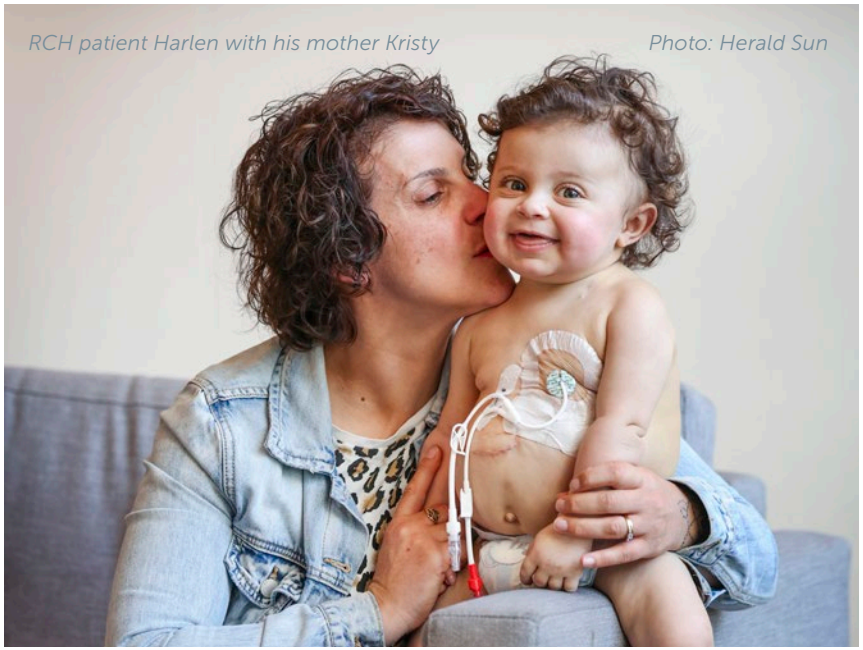
Life after transplant

Talking to your child about their liver transplant

Talking to children about their liver transplant can help them understand their health and feel comfortable asking questions.

For children who had a liver transplant when they were babies, parents can start by explaining in simple words that they had a special surgery to make them healthier. Parents can say the doctors needed to give them a new liver because their old one wasn't working well.

As they grow older, parents can share more details, like how the new liver helps their body work better and why it's important to take care of it. It's also good to remind children the transplant was done to keep them strong and healthy. Encouraging them to ask questions can make them feel more at ease and help them understand their journey.



RCH patient Harlen with his mother Kristy *Photo: Herald Sun*

Infections

Preventing infection

Here are some simple steps you can take to reduce the chance of getting an infection:

- Take your temperature regularly, especially if you feel sick.
- Talk to your doctor about getting a flu shot each year.
- Avoid being close to people who are sick.
- Keep yourself clean by washing your hands and keeping good personal hygiene.
- When gardening, wear gloves and wear a face mask if using potting mix.

Wash your hands

- Before preparing or eating food.
- Before and after touching wounds.
- Before touching your mouth, nose, or eyes.
- After touching pets or cleaning up after them.
- After gardening or touching soil.
- After changing nappies.
- After touching bodily fluids (like after blowing your nose).
- After touching anything that has touched human or animal waste.

Personal hygiene

- Take a shower with soap and water once a day.

Cleaning at home

- Clean your home often, about once a week.
- Wash clothes daily and bedding weekly.
- Use bleach-based cleaners for germs that can cause diarrhoea.

Outdoor activities

- Don't go barefoot outside.
- Wear shoes, socks, long pants, and long sleeves when gardening or spending time in nature.
- Wear gloves when handling soil, moss, or manure.
- Avoid areas with bird droppings, chicken coops, or caves to stay away from fungal spores.

Pets and animal contact

- Wait six to 12 months after a transplant before getting a new pet.
- Don't let pets sleep in your bed.
- Avoid cleaning bird cages, litter boxes, or animal waste. If you must, wear gloves and a mask.
- Keep pets healthy with fresh food and vet visits.
- Avoid handling wild animals, monkeys, reptiles, exotic pets, chicks, ducklings, and rodents. If you touch these animals or get bitten see a doctor straight away.

Signs of infection

A high temperature is often a sign of infection. Your transplant nurse will give you instructions on how to check for fevers at home and when you should contact the transplant unit.

Other signs of infection to watch out for include:

- chills or shaking.
- redness, swelling, or pain in your eyes, ears, throat, skin, joints, or belly.
- rash, sores, or blisters on the skin.
- diarrhea or vomiting.
- burning or blood when peeing or needing to wee more often.
- new or ongoing cough, shortness of breath, wheezing, or chest pain.

If you notice any of these signs, it's important to get medical attention as soon as possible.

Chickenpox contact

Most children who have a transplant after one-year-old have already been vaccinated against chickenpox. However, sometimes after the transplant, their immune system changes and they might lose protection from the vaccine. A few months after the transplant, doctors check if the vaccinations are still working. The transplant team will let you know if any vaccines are no longer effective.

For children who had their transplant before they got their first live virus vaccinations, or who have lost their chickenpox protection, it's very important to act quickly if they come into close contact with someone who has chickenpox. Family, friends, or school should let you know right away if there's a chance of exposure.

Most hospitals and some rural doctors have a product called ZIG (zoster immunoglobulin), which is given by injection and can protect against chickenpox for about three weeks. ZIG should be given within 96 hours of contact and can be given up to 10 days after exposure.

Close contact with someone who has chickenpox means living in the same house, being in the same room for an hour, or face-to-face contact for five minutes. If your child is immune to chickenpox, no action is needed if they come into close contact with an infected person.

Vaccinations

Children who have had a transplant should NOT get any "live" vaccines, such as:

- Measles, mumps, rubella
- Varicella Zoster (chickenpox)
- B.C.G (TB)
- Polio Sabin (oral)
- Yellow Fever Vaccine
- Typhoid (Typh-vax oral)

Always check with your transplant team about which vaccines are safe.

Children who had a transplant should avoid close contact with people who have just had a live vaccine for 48 hours after they get vaccinated.

We will check your child's vaccine status six months after the transplant and restart any needed vaccines then.

Dental care

After an organ transplant, your child might have problems with their teeth, like infections or gum overgrowth from medicine. Good mouth care is very important.

To help prevent dental problems:

- Brush teeth regularly with a soft toothbrush.
- Visit the dentist every six months.
- You might need antibiotics before any dental work.

See your doctor or dentist right away if your child's gums are swollen, tender, or red.

Nutrition

After a transplant, what your child needs to eat may be different depending on their health. Be sure to check with your child's transplant dietitian and doctor for any special food instructions.

Here are some general healthy eating tips:

- Choose foods that are low in fat (especially low in saturated fats), sugar, and salt, and use salt sparingly.
- Drink plenty of fluids, especially water.
- Keep food clean and safe by following good food hygiene practices.

Skin care

Your child may be at a higher risk of developing skin cancer or experiencing other skin problems. Teens might also get acne because of their medications.

To help prevent skin issues:

- Tell your doctor right away if you notice any unusual spots or changes on your child's skin.
- Try to stay out of direct sunlight, and always remember to wear protective clothing, sunscreen, and a hat—SLIP, SLOP, SLAP!

Wound and scar management

For most children the liver surgery site will be on the abdomen (Laparotomy) and possibly the lower chest.

What is a scar?

A scar forms as a part of the skin's natural healing process after a cut, burn, or scrape. Scars are a normal part of how the body repairs itself.

How does a scar mature?

Scars change as they heal. At first, a scar might look red and thick, this is called an "immature scar." Over time (usually between three months and two years), scars become lighter, softer, and flatter. When the scar is fully healed, it's called a "mature scar".

Wound care in the early weeks after surgery

Bathing

- A few days after surgery, your child can take a shallow bath or use a hand-held shower if your nurse says it's okay.
- If your child still has dressings on, try not to get them too wet. Most dressings are waterproof.
- If the dressings are removed, gently clean the wound with a damp, well-wrung cloth and pat the skin dry.
- About 10 days after surgery, when the wound is fully healed, your child can take a deeper bath or shower.

Wound care

- After leaving the hospital, extra wound care is usually not needed.
- Stop your child from picking at or scratching the wound. Let scabs fall off naturally.

Activity

- Your child will likely rest when they feel tired and become more active as they recover.
- They can sit or lie in any position that feels comfortable. If they are uncomfortable, they will let you know.
- For six weeks after surgery, avoid:
  - Contact sports
  - Heavy lifting
  - Too much physical activity

Clothing

Choose soft, loose, and comfortable clothes to avoid irritating the wound.

Long term scar management

Once the scar has healed completely (no scabs or open areas), you can help reduce scar formation by:

Massage

- Use a mild, fragrance-free moisturiser (like Sorbolene) to keep the skin soft and prevent irritation.
- If your child has sensitive skin, ask their doctor about the best moisturiser to use.
- Gently massage the scar in a circular motion with firm but comfortable pressure. Over time, you can increase the pressure as the scar becomes less tender. The massage should never hurt.
- Massage helps soften the scar and the tissue underneath.

Taping

- Use Micropore tape to keep the scar from becoming wide or raised.
- Once moisturiser has soaked in, gently press the tape firmly over the scar
- The tape can stay on for up to a week but can be replaced earlier if it falls off.
- Keep taping the scar for 6-12 weeks to help it heal.
- Micropore tape can be bought at most pharmacies and comes in white or skin-coloured options.

Desensitisation

Sometimes scars feel extra sensitive because of changes in the nerves in the skin. Desensitisation can help the nerves return to normal.

Collect items with different textures (like a comb, cloth, spoon, feather, face washer, or ribbon). Use these to gently rub or tap the scar to reduce sensitivity.

When to worry about a scar

Most scars heal well, but if you notice problems, your child may need help from a physiotherapist trained in scar care.

Look out for scars that are:

- Purple or red for a long time
- Hard
- Limiting movement
- Raised and affecting appearance

If you have concerns, talk to your doctor.

Exercise

Exercise is an important part of recovery after a transplant. It will help your child feel better, stay fit, and manage their weight. The type and amount of exercise your child can do will depend on their health, so always check with the transplant physiotherapist and doctor to make sure it's safe. Water activities, like swimming, should be discussed with the transplant doctor or nurse because of the risk of infection.

Here are some general exercise tips after transplant:

- Start with gentle, regular exercise like walking or cycling.
- Slowly increase fitness by adding more time and making exercise a bit harder.
- Avoid contact sports, like football.
- Ask your transplant team about any weight limits for lifting for at least three months or until your doctor advises.

Alcohol

Drinking alcohol can cause dehydration and lower blood flow to the new organ. People who have had a liver transplant should not drink any alcohol.

Smoking

Children and adolescents should not smoke while waiting for or after transplant. Every year, thousands of Australians die because of smoking. Cigarettes have poisons that are very harmful to your health and can shorten your life. Smoking can also affect things like fitness, fertility and your child's skin. For help with quitting smoking, call the QUIT line.

Sexual health

Starting or returning to sexual activity after a transplant is different for everyone, and it's okay to have questions. The transplant team can give tailored advice based on your health. After a transplant, some people may feel less interest in sex or may have some sexual difficulties. There are different reasons for this, so it's a good idea to talk to the doctor, transplant coordinator, or nurse if you are experiencing any issues. Most of the time, these problems can be worked out.

If someone is sexually active after a transplant, it's very important to practice safe sex. Using condoms can help protect everyone from sexually transmitted infections (STIs), like chlamydia or HIV, which can affect health and even the new transplanted organ. Safe sex also helps prevent unplanned pregnancies. After a transplant, pregnancy can be complicated and may need special planning with the doctors, so it's best to avoid unplanned pregnancies.

Women's health

Women should remember to keep up or improve their health check-up routines. Once they are sexually active, they should have a yearly pelvic exam. Women aged 25 years or older will need a Cervical Screening test every five years.

For female transplant recipients who stopped having periods because of their illness before the transplant, periods may start again after the transplant. Steroids may stop periods, but ovulation (when an egg is released) can still happen, so pregnancy is still possible.

Fertility and pregnancy

It's possible to have a successful pregnancy after a transplant. However, most doctors recommend waiting until your health and the transplanted organ are stable before thinking about having a baby. Transplant recipients should always talk to their transplant team when planning a pregnancy to keep both the mother and baby safe. Some medicines might make it harder to get pregnant or could be risky for the mother or baby during pregnancy.

Men's health

After your transplant, when you are 18 or older, you should get screened for testicular and prostate cancer. Finding these cancers early makes treatment easier and more effective. Your GP (family doctor) can do a regular testicular and prostate check-up for you.

Tattoos and body piercing

For transplant recipients, it's very important to think carefully about getting a tattoo or piercing, making sure it doesn't affect your health. Transplant recipients have a higher risk of infections and other problems, so you should always talk to your doctor before getting a tattoo or piercing. Do not get any tattoos or piercings in the first 12 months after your transplant or for eight weeks after being treated for rejection. If you're thinking about getting a tattoo or piercing, ask your transplant CNC for more information.

Driving

Transplant recipients should check with their local authorities about any rules or restrictions for people who have had an organ transplant. Your transplant team can let you know when it's safe for you to start driving a car again.

Returning to education or work

Going back to school, your old job, or starting a new one is an important goal for many transplant recipients. Talk to your transplant team about when it's a good time to do this. Usually, it's best to wait about three months before returning to school or work. This waiting period helps lower the risk of infection and allows time for regular medical check-ups. Your child's health and any physical limitations should be considered. Your child may find it better to return to work part-time until they feel stronger and energy improves.

Travel information

Things to think about before travelling:

- Choose your destination carefully. Think about your child's current health, any physical limitations, and the sanitary conditions of the country you're visiting. Find out where the nearest medical help is in case you get sick.
- Consider travel insurance. You may need to search for a company that offers insurance to people who have had a transplant.
- Get a doctor's letter. Ask your doctor for a letter listing medications and a short medical history. Medic Alert tags are also a good idea.
- Talk about vaccinations. Discuss any needed vaccinations with your doctor at least three months before travelling.
- Pack extra medication. You may not find the same medication in other countries, so bring more than needed.
- Store medication safely. Seal it in an airtight container, protected from heat and light.
- Split your medication. Keep some in your hand luggage and some in your suitcase in case either one is lost.
- Check with your airline. If you need medication in your hand luggage, ask if you need a medical certificate.
- Bring contact information. Take your transplant team's contact numbers and get details for hospitals or transplant units in the area you're visiting.
- Pack a basic medical kit. Include a thermometer and medicines for cuts, bruises, nausea, and diarrhea.
- Ask for help if needed. If you're unsure how to adjust medication times, your transplant coordinator or nurse can help.

Procedures and investigations

Medical Imaging

Ultrasound

An ultrasound is a test that uses sound waves (that we can't hear) to make pictures of different parts of the body. To do this, a special gel is put on the skin, and a small microphone is moved over the area. The test usually takes between 15 to 60 minutes, and the child lies on a table on their back, side, or stomach. It doesn't hurt, and nothing goes into the skin. Ultrasounds can show if there are any problems with organs like the liver, gall bladder, pancreas, spleen, and kidneys.

There are different types of ultrasounds:

- **Liver Doppler** checks the blood vessels that bring blood in and out of the liver and the bile duct. It also looks at the spleen and kidneys.
- **Vessel Doppler** examines big blood vessels that carry blood to and from the heart.
- **ECHO** looks at the heart's structure, how it works, and how blood flows through it.

Magnetic Resonance Imaging (MRI)

An MRI scan is a test that uses radio waves and a strong magnet to take pictures of the inside the body. It does not use x-rays or any radiation, so it's a safe, painless, and non-invasive test.

The MRI machine is large and shaped like a cylinder, open at both ends, with a bed that has a headrest. The bed moves into the middle of the machine. It's important to stay very still during the scan. Since the machine makes loud knocking sounds, headphones and videos are available to help kids feel more comfortable. Young children or kids who have trouble staying still might need medicine to help them sleep during the scan.

PET MRI This special scan combines MRI with another scan called PET, which looks for changes in cells. PET MRI helps doctors see how well organs and tissues are working, and can help find any problems early.

MRCP This is a type of MRI that shows clear pictures of the liver, bile ducts, gallbladder, and pancreas. It helps doctors see the shape and structure of these organs to check if everything is healthy.

CT Scan

A Computerised Tomography (CT) scan, also called a CAT scan, uses X-rays to take detailed pictures of parts of the body. The CT machine is shaped like a big, open doughnut.

Your child will lie on a table that moves in and out of the machine to take the pictures, and they need to stay very still. Sometimes, they might need to hold their breath for a few seconds, but usually for no more than 10 seconds. Most CT scans take about 10-15 minutes.

For some scans, like abdominal scans, your child may need to drink a special liquid to help show the stomach and intestines. If blood vessels need to be seen clearly, a contrast dye might be injected. Since the radiologist decides if contrast is needed right before the scan, children usually don't eat or drink beforehand. If an injection is needed, a numbing cream (Angel cream) is put on the skin 30-60 minutes before to make it more comfortable.

X-ray

An X-ray is a quick and simple test that uses a small amount of radiation to take pictures of the inside of the body. It helps doctors see bones and organs to find out if there are any problems. The X-ray machine is like a big camera, and the child usually stands or lies still while the picture is taken.

Liver Biopsy

A liver biopsy is a test where doctors take a tiny piece of the liver, put it on a glass slide, and look at it under a microscope. This helps them learn more about any problems in the liver. While the child is under anaesthetic, a small needle is used to take the sample, and the area is numbed first to make it more comfortable. This test helps doctors understand liver conditions and decide on the best treatment.

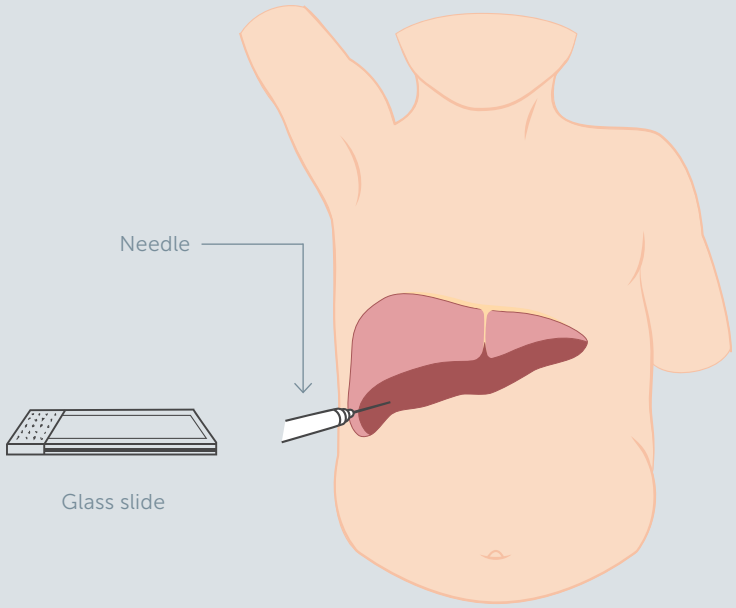


Figure 8. Liver biopsy

Percutaneous Cholangiogram (PTC) and Dilatation

This procedure is performed while the child is asleep under general anaesthesia. A special dye is injected into the bile ducts using a thin needle that goes through the skin and into the bile ducts. This dye helps doctors see the size and shape of the bile ducts inside and outside the liver.

To prevent infection, children are given antibiotics through a vein before this test. This test helps doctors find out if there is damage or a blockage in the bile ducts. If there's a narrow or blocked area, doctors can use a thin wire and a small balloon to stretch it open, or they might place a stent (a tiny tube) to keep it open. After the procedure the child may need to have a small tube stay in place, until another the next procedure to stretch the narrowed area.

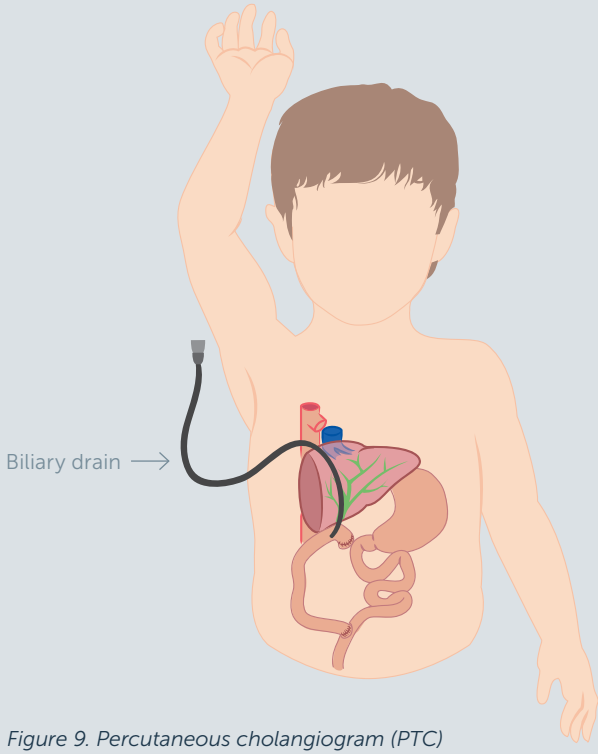


Figure 9. Percutaneous cholangiogram (PTC)

Venography and Angiography

Venography and angiography are tests that help doctors see blood vessels (like veins and arteries) in the body. In these procedures, a special dye is injected into the blood vessels, making them show up clearly on X-ray images. Venography looks at the veins, while angiography checks the arteries. This helps doctors find any problems, like blockages or narrow spots.

A "plasty" is a treatment that helps open up a blocked or narrow blood vessel. A small balloon is placed in the area and then gently inflated to widen the vessel. Sometimes a tiny tube, called a stent, is also put in to keep the vessel open. This helps blood flow smoothly through the body.

Ascitic Tap (Paracentesis)

A small needle is injected into the belly area to remove extra fluid that has built up there (called ascites).

Sometimes, a thin tube is left in place after the procedure so that if more fluid builds up, it can be drained more easily. This procedure is done while the child is asleep under general anaesthesia.

Other tests

ECG

An ECG, which stands for Electrocardiogram, is a test that checks how the heart is working. Small, sticky patches with wires are placed on the chest, arms, and legs to pick up the electrical signals that the heart makes when it beats. These signals are shown as a line on a screen or paper, which helps doctors see if the heart is beating normally. An ECG is quick, safe, and doesn't hurt. It helps doctors find out if there are any problems with the heart's rhythm or function.

Respiratory Function Test

Liver disease can sometimes affect how well the lungs work.

The Respiratory Function Test checks how well the lungs are working and it takes about 45 minutes. During the test, the child blows into special instruments that measure how much air the lungs can hold and how well the lungs can move gases through them. Sometimes a blood sample is also needed for this test.

Younger children who can't follow instructions are not able to do the Respiratory Function Test.

Gastroscopy

A gastroscopy is a procedure that looks inside the throat (oesophagus), stomach, and the first part of the small intestine (duodenum).

The doctor uses a long, flexible tube called a gastroscope that has a light and camera on the end. The gastroscope goes through the mouth, down the throat, into the stomach, and then into the small intestine.

During this procedure, the doctor usually takes small samples (biopsies) of the lining of these areas for testing. Children are placed under general anaesthesia so are asleep during the procedure.

Patient stories

Morgan's story

Morgan was nine-years-old when she received a liver transplant—a life-changing event that has made a huge difference in how she lives. Born with the rare liver condition Biliary Atresia, she had long struggled with fatigue and low energy, which affected her daily life.

Leading up to the surgery, Morgan experienced a blend of emotions, including excitement and curiosity about the procedure. "It was really reassuring to talk to the doctors," she recalled. "I knew my life was going to change." The support she received from family and friends during this time was invaluable. "They visited me, asked questions, and made me feel supported," Morgan remembered, highlighting the important role their encouragement played in her journey.

Following her recovery, Morgan has regained a sense of vitality and now enjoys activities that once felt out of reach. "I feel like I can do more now. Life is easier," she said, reflecting on the positive changes that have come with her new lease on life.

While she still requires regular medical check-ups and ongoing medication, Morgan now faces life with a renewed sense of confidence and determination. "It's nice to know someone gave me a second chance at life," she shared. Morgan's positive attitude shines through as she looks forward to the future, ready to take on new adventures, knowing the transplant has helped her to live a full and active life.

"I can now run really long distances...it's amazing to finally know what it feels like to have energy."

- RCH patient Morgan

Harry's story

At the age of one Harry was placed on the transplant list due to a rare genetic condition known as Propionic acidemia, a metabolic disorder that impacted his early development. After a year of waiting his family received the long-anticipated call. The journey to a liver transplant had its challenges, including two false starts before the actual procedure was scheduled.

Anna, Harry's mother, recalls the moment they received the call with clarity. "I remember where I was in the house ... my knees gave out and I dropped on the concrete floor." Despite the uncertainty surrounding the situation, the family found reassurance in the care provided at The Royal Children's Hospital. "The surgeons at The Royal Children's Hospital are amazing. They're all very knowledgeable, and we're very lucky."

Harry's recovery was a difficult yet inspiring process." During those weeks when he was awake and alert... every day marked a new level in his recovery," Anna noted.

Three years later Harry is described as "more stable metabolically than we could have ever even fathomed." He is thriving, approaching life with renewed energy and joy. His family expresses deep gratitude for the second chance he has been given and anticipates many more milestones in the future. "He loves life," Anna stated.

"You've got to go in with an open mind... it's not going to be smooth or perfect, but it's worth it. Trust the team, trust the doctors, and trust the nurses because they really want the best for your kid."

– Anna, RCH patient Harry's mother

Marley's story

Marley was diagnosed with Biliary atresia at six-weeks-old and within the next year, her family was told she would need a liver transplant. This diagnosis led to an emotionally challenging period as her parents, Sarah and Craig, faced the uncertainty of waiting for a donor liver.

Craig recalls, "I can't express how difficult it is to not know ... when that date is going to be. You are managing, but you're watching your baby get, you know, much more unwell," he shared, noting the frequent hospital visits as Marley's condition worsened. Despite this the family never felt fear about the transplant itself. "It was relief" Craig said.

When a liver became available, they underwent a "dummy run" where they were prepared for the transplant but ultimately declined the liver as it wasn't optimal. "It's heartbreaking, but we wouldn't want a liver that wasn't 100% suitable for Marley... it was worth waiting that little bit longer."

Following the successful transplant, Marley's recovery has brought immense joy to the family. Sarah described walking out of the hospital with her daughter and the feeling of normalcy returning.

"Marley is in daycare two days a week, she goes to parties, she goes to the pool. Life is very, very normal for us," she said.

The support of family and friends during this time was invaluable, as Sarah added, "You cannot go from having a sick child and getting to transplant alone."

Today, Marley is described as "unstoppable," making up for lost time and embracing life with newfound energy.

"To have a child that is happy and not feeling sick is such a joy. Walking out of that hospital, and into the sunshine, was one of the best feelings in the world."

- Sarah, RCH patient Marley's mother

Thomas's story

At just 14-years-old, Thomas was rushed to the hospital. Initially he was thought to be suffering from a stomach bug. After a long night in the emergency department, his family received life-changing news: Tom would need a liver transplant.

"Tom had only been unwell for a couple of days when he was diagnosed with acute liver failure and the decision was made that the liver couldn't be saved and he needed a transplant," recalls Tom's mother, Amanda.

Just three days after being placed on the waiting list, Tom was moved into surgery. Though he underwent several additional procedures after the transplant, Amanda took comfort in knowing the ICU staff were exceptionally skilled at what they do.

Despite the unexpected and overwhelming nature of the situation, Tom found it helpful to request simpler explanations when he didn't understand what was happening.

Now Tom is back at school, spending time with friends, and living life like any other teenager. "I missed out on maybe two months of school. That's about it. Nothing really changed. Now, I've got a cool story."

"We were fortunate to be able to put our lives on hold because of the incredible support from our community, friends, and family," Amanda shares with gratitude.

When discussing the donation, Amanda becomes emotional, reflecting on the profound gratitude they feel. "We're just so thankful... it's the greatest gift you can possibly give."

Tom's journey, though challenging, has only deepened his family's appreciation for the power of community, family, and the life-changing impact of organ donation.

Notes

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