

A Reference Guide For the Care of Your Child's Biliary Drain



Percutaneous Transhepatic Cholangiography and Biliary Drainage

The Transplant team has recommended a procedure called a PTC — percutaneous transhepatic cholangiogram. As the PTC is being done, the physician may decide that a biliary drain needs to be placed.

This booklet will provide you with information regarding your child’s percutaneous transhepatic cholangiogram (PTC) with biliary drain placement. This booklet also has information about why your child needs the PTC, how to care for the biliary drain, how to change the dressing and participating in normal routine childhood activities after drain placement.

Phone Numbers

Transplant Coordinator

Pediatric Transplant Coordinator On-call
(Pediatric liver transplant)..... 877-640-6746

Transplant main office 412-692-6110

Interventional Radiology

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What is a PTC?

Percutaneous Transhepatic Cholangiography (PTC) is a procedure to look at the bile ducts of the liver. The procedure is performed by an interventional radiologist who is skilled in performing procedures, such as PTC's using special x-rays and ultrasounds.

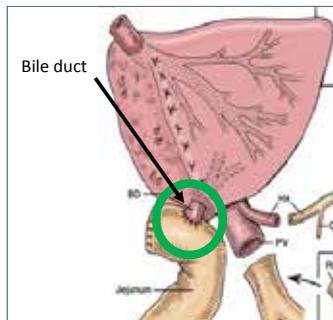
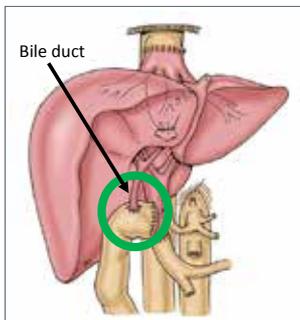
Why does my child need a PTC?

The liver plays an important role in hundreds of bodily functions. Liver cells make a substance called bile, which leaves the transplanted liver through a bile duct (green circle) that is sewn to a piece of intestine (roux limb). Bile contains waste

products and also helps with fat absorption. The bile duct may become narrowed (strictured) preventing bile from leaving the liver.

If bile isn't draining from the liver, your child may develop:

- elevated liver tests, especially the gGTP
- fever from bile infection (cholangitis)
- right upper abdominal pain
- itchiness
- yellowing of the whites of their eyes
- pale stool
- leaking bile into the abdomen



How is a bile duct issue diagnosed?

1. Liver function tests

- If your child's liver numbers are elevated, your transplant team will need to figure out why the numbers are high.
- Enzymes are located within different cells of the liver and escape into the blood when cells are damaged.

- Elevation in bilirubin causes yellowing of the eyes and urine and is a late finding.

Numbers alone cannot tell us what is causing damage to the liver and all are often elevated in rejection, or infection and bile duct strictures.

Test	Name	Location	Normal Range
Bili	Total bilirubin	Blood	0.1 - 1.2 mg/dl
ALT	Alanine aminotransferase	Liver cells	< 40
AST	Aspartate Aminotransfer-ase	Liver cells	< 40
gGTP	gamma-Glutamyl transpepti-dase	Bile duct cells	< 44

2. Ultrasound

An ultrasound can be used to look at the liver to see if any bile duct dilation is present. Even if the ultrasound does not show bile duct dilation, there could still be bile duct dilation present. Ultrasound also tells important information about blood vessels and flow within the liver.

3. Liver biopsy

A liver biopsy may be performed to help diagnose the cause of elevated liver function tests. When the problem is the bile duct, the biopsy usually demonstrates:

- **Cholangitis:** infection and inflammation of the bile ducts
- **Cholestasis:** plugging of bile in the liver
- **Ductular proliferation:** The liver responds to bile duct problems by trying to change liver cells into bile duct cells.

4. MRCP (Magnetic Resonance CholangioPancreatogram)

An MRCP is a special MRI of the liver that looks specifically at the bile ducts and the pancreas and is the most accurate non-invasive way to diagnose biliary problems.

5. PTC (Percutaneous Transhepatic Cholangiogram)

PTC is the most sensitive way to diagnose biliary strictures. After the patient is asleep, a needle is used to inject contrast (dye) into the bile duct and x-rays are used to see the contrast fill the bile duct and hopefully empty into the intestine. If this test shows a narrowing, in any of the bile ducts, a tube (catheter) will be passed into the dilated duct to help fix it.

The Procedure

Preparation

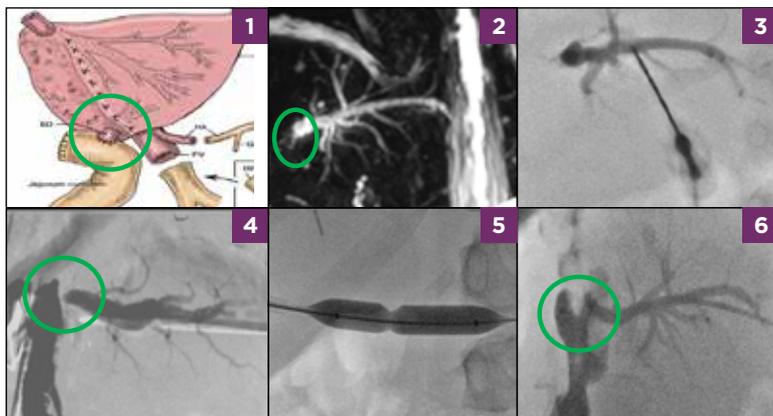
A PTC will be planned if the non-invasive tests and biopsy suggest a problem with the bile duct. PTC will allow us to confirm a problem and start to treat it. Prior to your PTC procedure your coordinator will ask you to get blood tests completed and will let you know if any other studies are needed. Once the procedure is scheduled, you be notified when to come to same-day surgery and when to have your child stop eating and drinking.

The procedure

PTCs are done by radiologists with special training. The radiologist and liver transplant physicians communicate with each other about the PTC results. Your child will be given anesthesia so that they will not hear or feel anything during the procedure. Your child will be monitored closely during the procedure and will also receive antibiotics.

If your child is allergic to any medications or betadine, it is very important to tell the radiology staff!!

The radiologist will use ultrasound to insert a needle through the skin into a bile duct within the liver and inject contrast (dye). The dye appears black on x-rays and allows the radiologist see if there is a narrowed area. If there is a narrowing, the radiologist will guide a thin, flexible catheter into the duct and a special balloon may then be used to dilate the narrowing. If the radiologist cannot dilate the bile duct by using the balloon, they carefully guide the catheter through to the bile duct that is not working properly. A small drain (a "PTC catheter") is then passed across the narrowed bile duct and possibly into the intestine. The PTC catheter passes from the intestine, through the bile duct and out the skin.



1. Diagram of a segmental liver transplant—notice the bile duct sewn to the intestinal Roux limb (green circle)
2. MRCP image of a dilated bile duct and a stricture (green circle)
3. Initial PTC image of a dilated bile duct being filled with contrast by injecting it with a needle
4. PTC image showing a bile duct stricture where it is sewn to the intestine. Notice the roux-limb of the intestine fills with con-trast, but there is a narrowing at the point where they are joined together (green circle)
5. A balloon is being used to dilate the narrowing
6. After several dilations over several weeks, there is no longer a narrowing.

Sometimes, the catheter cannot pass into the intestine and it will be left in place as an external drainage catheter. This will be discussed later in this book.

Most children need to have several repeat PTC procedures over the course of several weeks. With each subsequent procedure the bile duct may be dilated with a balloon and have a larger catheter placed to improve bile drainage. The interventional radiology department will inform you of when your next appointment will be.

After the procedure

After the PTC with biliary drain placement is completed by the interventional radiology team, your child will recover in the post anesthesia care unit (PACU). Your child may also receive an antibiotic in the recovery room. Because the bile is “backed up” in the liver there is a risk of infection when the radiologist injects the dye to look at the bile ducts. If your child develops a fever in the recovery room or looks unwell

you may be admitted overnight for observation.

Remember to bring all of your child’s medications along with clothing and all supplies with you in case you need to stay overnight after your child has the PTC.

If this is your child’s first PTC with biliary drain placement your child will be admitted to the hospital and observed for any bleeding and signs of infection!

A member of the interventional radiology team will meet with you prior to discharge to complete a teaching session on how to care for the biliary drain. You will be provided with all of the supplies necessary for the drain care.

After 48 hours, if there is no fever or signs of illness, the drain will most likely be clamped/capped to allow the bile to flow naturally through the liver and into the intestine. You will be informed when to clamp/cap the drain. A repeat procedure will be scheduled for you prior to discharge.

You may need to stay overnight after the repeat procedure so please bring all of your child's medications and supplies with you to every PTC procedure.

Once you are home it is important that you monitor your child for any fever. Please check your child's temperature if you think that they may have a fever. If your child has a fever you will need to call your transplant coordinator or the on—call transplant coordinator! Some drains do not need to be flushed and others need to be flushed. You will also be informed if you need to flush the drain and how often you will need to flush the drain.

Types of biliary drainage catheters

There are two types of biliary drainage catheters that are placed:

1. external drainage catheter
2. internal-external drainage catheter

External drainage catheter

An external drainage catheter goes through the skin into the liver and is placed in a bile duct that is above the stricture or obstruction.

This catheter remains in place to help drain the bile out of the liver. If the drain is an external drain, it means that all other attempts to pass the catheter into the bile duct and past the stricture or obstruction have failed.

An external drain is placed to allow the bile to drain and then another PTC with biliary drain placement will be scheduled to attempt to place and advance the catheter through the stricture or obstructed area.

If you have an external only catheter you will not “flush” the catheter unless instructed, since there will always be bile draining from the catheter.

Never “clamp” an external drainage catheter unless you are informed to clamp the catheter by the radiology or transplant team. Clamping an external catheter could make the bile

“back up” and start to leak from the skin insertion site. Leaving the catheter open to a drainage bag allows free flow of the bile and is generally better for the liver.

If the bile stops flowing through the catheter and starts leaking from the skin site there may be something blocking one of the holes of the catheter. Call your coordinator or the on call coordinator. The coordinator may have you flush the catheter with a small amount of sterile saline to clear the obstruction.

If the bile stops flowing, or is leaking from the skin, or if your child has a fever or is not feeling well call you post-transplant coordinator or the on call transplant coordinator.

Internal drainage catheter

An internal- external biliary drainage catheter goes through the skin into the liver into the bile duct and continues through the obstructed area and ends in the small intestine.

The end of the catheter that is outside of your child's abdomen, the external drain, is connected to an external drainage bag that will collect bile. The other end of the catheter, the internal end, which is in the small intestine, allows the bile to pass into the small intestine. There will be a stopcock located at the end of the external drain and before the drainage bag. You will be taught how to position the handle on the stopcock so that you can appropriately flush the internal part of the drain.



Caring for the Biliary Drain



Care of the PTC biliary drain

Once you are home you will need to do the following care of the drain:

- change the dressing
- change the catheter holder
- flush the catheter, if told to do so
- change the catheter tubing
- change the drainage bag
- stopcock

Then,

- change the dressing
- change the catheter “holder”/ stay fix device
- flush the catheter as directed (remember internal only catheters are routinely flushed)
- measure and record the amount of bile drainage

Dressing change

The dressing should be changed one time per week and as needed if the dressing becomes loose or wet.

Gather all needed supplies:

1. Chloraprep
2. Fixation devise
3. Clear occlusive dressing

Dressing change

- Wash your hands with soap and water rubbing the hands together for 15 seconds then rinse. Dry your hands with a disposable (paper) towel.

- Put on non-sterile gloves and remove the old dressing.
- Activate the chloraprep wipe and clean the insertion site of the skin starting closest to the catheter and continuing to the outer abdomen in a circular motion. Once to the outer abdomen, do not go back towards the to the insertion site with the same chloraprep!
- Allow chloraprep to dry, do not blow or fan the area to make it dry faster!!
- Apply stay fix device
- Remove the backing from the occlusive dressing and apply to the skin.
- Clean area in a circular manner, starting close to the drain and then moving to the outside.



Stat lock or stay fix change

The Stat lock or Stay fix should be changed every two weeks and as needed if it becomes dislodged from the skin or becomes soaked from leakage of bile **from the insertion site**.

- Clean site and allow to dry then attach back piece of stay device.



- Apply top piece of stay device dressing, securing drain between the bottom and top pieces



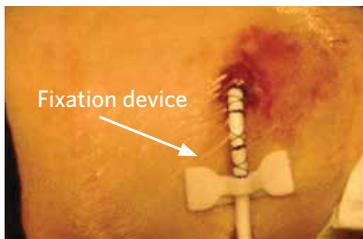
- Drain with stay fix device



- Stay fix and clear occlusive dressing over insertion site



- Apply dressing over insertion site, stay fix device and drain
Capping/clamping the drain



- Drain with stay fix device and dressing applied. Stay fix device is changed every 2 weeks



Capping/clamping the drain

After 48 hours, if there is no sign of (illness) fever, abdominal pain or discomfort, the drain will be capped. This will allow the bile that the liver cells make, to flow naturally through the bile ducts, out of the liver and into the small intestine. You will be informed when to cap the drain. If your child experiences any discomfort after the catheter has been capped, or develops a fever, call your transplant coordinator or the on — call coordinator.

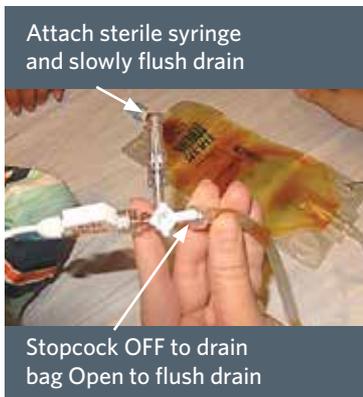
Flushing the drain

You will be told if you need to flush the catheter. Since bile is thick and sticky it can clog the holes of the catheter blocking the bile from draining. You will only need to routinely flush drain if your child has an internal catheter, meaning that the catheter goes in through the stricture and the tip sits in the small intestine. An external drain will only be flushed if you are directed to do so. You should flush only with the amount instructed. If you feel resistance, your child has pain with flushing or you see leakage of saline from the insertion site at the skin stop flushing and call your transplant coordinator or the on call coordinator.

Flushing the drain:

- Gather supplies:
 - > Alcohol wipes,
 - > Sterile syringe with saline
- Wash hands well and dry
- Open sterile saline syringe package but do not remove syringe from package

- Using alcohol wipes, vigorously clean the hub of the cap for at least 5 seconds
- Remove syringe from sterile package and insert the end of the sterile syringe with the correct amount of sterile saline needed to flush the catheter
- Turn the handle of the stopcock off to the bag, the handle should be pointing towards the bag
- Slowly push the plunger down on the syringe to irrigate the drain
- **If you feel any resistance or if it is hard to flush STOP**
- **If your child experiences pain when flushing STOP**
- **If you see saline leaking from the insertion site STOP**
- Turn the handle of the stopcock off to the port that the syringe is attached to; the handle should be pointing straight up
- Remove the syringe and properly dispose of it



Bathing with a PTC in place

Bathing is permitted while your child has a biliary drain. Cover the dressing with a water proof plastic wrap. If your child has a drainage bag:

- Turn stopcock off to the drain
- Clean where the bag connects to the stopcock with an alcohol wipe

- Disconnect the drainage bag and stopcock and place a sterile cap on the end of the drainage tube. Some drainage may leak out before you place the cap on the end. This is o.k.
- Cover the dressing with water proof plastic wrap
- Bathe
- Dry the dressing site and then proceed with dressing change if needed.
- Clean where the sterile cap connects to the tube, remove the sterile cap and reconnect the drainage bag and stop cock.

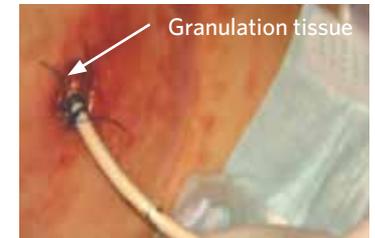


Potential Complications with a biliary drain

- Leakage around the insertion site on the abdomen
- Catheter dislodgement with exposed side holes
- Skin irritation, redness, skin breakdown, granulation tissue (raised skin at the insertion site)
- Dehydration because of high bile output into drainage bag

If any of these complications occur, call your coordinator or the on call coordinator.

If the bile drainage is increasing, call your coordinator or the on call coordinator or take your child to the nearest emergency department.



Helping your child understand the procedure

Care of your PTC Drain:
Psychosocial Aspects of Care

How to explain it to your child:

- Use developmentally appropriate language. For example, young children will best understand that a PTC drain is a way to drain bile from your liver transplant; whereas older children can understand the ductal system and how a catheter can improve liver function.

- **Expect your child to have feelings about the drain placement.** Some children feel frustrated that they require additional medical interventions, some are embarrassed about showing their friends or teachers, some are angry. Validate how your child feels and give them space to talk about it.
- **Help your child understand it may not be a one-time procedure.** PTC's with biliary drain catheters are often in place for many months, and often require frequent replacement. Depending on your child's age it may be helpful to prepare them a day or two in advance of the procedure.

Partnering with Your Child's School/Daycare:

Many families find it helpful to reach out to the school after biliary drain placement to make them aware of the change in their child's care. **Provide basic educational information** to school staff who will be caring for your child.

It can be helpful **to anticipate issues that may arise with the catheter/drain, and plan accordingly.** For example, in case of a leak, you may wish to have a change of clothing available at school and talk with the teacher about allowing the child to quietly be excused from class and discretely change without drawing attention to his/herself.

Partner with your school nurse about how to handle technical issues that may happen with the drain, and have a plan about who the nurse can call with questions and how to contact you. Make your child aware of this plan – it can reduce anxiety for a child to know how issues will be handled.

Helping Your Child Manage Peer Interactions:

- Help your child decide how much information they want to share about the biliary drain and with whom. Most times, as long as the school nurse and classroom teacher are aware of the change in medical care that is sufficient to handle most problems that may arise.
- However, one component of healthy coping with complex medical care is learning how to share your medical information with others. Below is a list of questions that peers typically ask. Most times, children ask these questions out of curiosity, and helping your child create a brief, clear answer will eliminate any unwanted follow up questions.
 - > "What's that?"
 - > "Why do you have it?"
 - > "What does it do?"
 - > "What's inside the bag?" (for external drains)

- > "What happens if it falls out?"
- > "Can you still go to gym class?"
- Develop an "out statement." Help your child learn to end the conversation if they don't want to answer any other questions. For example, "Thanks for asking, I don't want to talk about it now. Let's go color."
- There are no right or wrong answers to these questions. Work with your child to develop responses that they are comfortable with and share the degree of information they would like to share.

Signs your child could benefit from psychosocial support:

- Drastic changes in mood, anxiety, or interest in activities.
- Big changes often signal that children are struggling to cope.
- Hesitation or refusal to participate in activities, attend school, or attend other public outings.

- Refusal to discuss aspects of their medical care with parents/caregivers or medical team.

If you have concerns about how your child is coping with their biliary drain/catheter or other aspects of their medical care, please reach out to your coordinator, who can contact Transplant Social Work, Child Life, or Psychology to help your family.

Glossary of terms

ALT: Alanine transaminase is an enzyme most specific to the liver but can be found in the kidney, heart muscle and pancreas. The ALT becomes elevated when the liver becomes damaged or diseased.

AST: Aspartate transaminase is an enzyme that is found in red blood cells, liver, kidney, muscle tissue, pancreas and kidney. The AST is elevated when there is heart or liver become damaged.

Anesthesia: Special medication administered by doctors to help sedate patients so they won't feel, see or hear anything.

Betadine: a cleaning solution that removes germs from the skin.

Bile: a fluid made by hepatocytes, the liver cells that is secreted into the bile ducts and then into the small intestine to help absorb fats.

Bile duct: a vessel in the liver that carries bile from the liver cells to the common bile duct. The common bile duct then carries bile into the intestine.

Catheter: a flexible tube that enters or exits the body. Catheters may be used to drain body fluids (a Foley catheter drains urine) or to administer fluids or medications through a vein (a Broviac catheter).

Cholangitis: A bacterial infection in the bile ducts of the liver. Cholangitis can occur if bile flow is obstructed due to scarring of the duct or an obstruction in the duct. Symptoms of cholangitis may include fever, an elevated bilirubin level, jaundice. Antibiotics are used to treat an episode of cholangitis. Patients with recurrent cholangitis may be prescribed a preventative dose of antibiotic daily.

Cholestasis: bile flow out of the liver is either blocked or greatly slowed and the bile accumulates in the liver.

Dilate: to open or make bigger.

Ductular proliferation: a response of the liver to injury and the liver begins to rapidly make bile ducts.

gGTP: Gamma glutamyl transpeptidase is a liver enzyme most specific to the bile ducts and liver. The GGTP will become elevated with diseases that affects the bile ducts and with general liver disease.

Granulation tissue: an overgrowth of skin/tissue, usually at the insertion site of a tube or drain

Jaundice: a yellow appearance of the skin and eyes commonly seen in patients with liver disease. Jaundice results from an increased amount of bilirubin in the body, which is usually excreted in bile.

MRCP: a specific MRI that shows the bile ducts and if there is a problem with any of the bile ducts.

