Pulmonary Thromboendarterectomy Surgery

Information for patients with chronic thromboembolic pulmonary hypertension (CTEPH) and their families

Read this booklet to learn:

- how to prepare for your surgery
- what to expect while in hospital
- what to expect after you return home
- who to call if you have any questions

Your surgery has been scheduled for: Date:	
Time:	
You will need to come to the hospital on: Date:	
Time:	
You can expect to stay in the hospital for about:	

Toronto Chronic Thromboembolic Pulmonary Hypertension (CTEPH) Program "To optimize the care of patients with CTEPH in Canada"



Doctors of Thoracic Surgery®





Preparing for your surgery

What type of surgery am I having?

Your surgeon has scheduled you for pulmonary thromboendarterectomy (PEA) surgery. You and your health care providers have decided that this surgery is the best treatment for your chronic thromboembolic pulmonary hypertension (CTEPH).

This surgery has 2 goals:

1. To improve the blood flow in your lungs and treat your shortness of breath.

If you use oxygen, you may slowly reduce the amount you use over many weeks or months after surgery. You may also be able to return to your normal activities and become more active. This will improve your quality of life.

2. To prevent the right side of your heart from weakening because of high blood pressure in your lung (pulmonary) vessels. Removing clot and scar tissue in your vessels lowers the pressure in your lungs. This reduces how hard the right side of your heart has to work.

How long will I need to stay in the hospital?

Be prepared to stay in the hospital for about 10–14 days. When you can go home will depend on how you are recovering.

Can the time for my surgery change?

Yes, but it is unlikely. We will do our best to do your surgery at the scheduled time. But, your surgery may be rescheduled if your surgeon needs to do emergency surgery.

Choosing a support person

Before your surgery, you need to choose a support person. This is a person who will be available to help you at the end of your hospital stay and take you home.

Your support person can be a family member or a friend. They will need to agree to come to the hospital when you are discharged and take you home. Give your support person's name and phone number to the Toronto CTEPH Clinic office before your surgery.

What about my medicines?

If you are taking a blood thinner medicine by mouth or by needle, it's important to keep taking it. Your doctor or nurse practitioner will stop your medicine once you are admitted to the hospital.

Your hospital stay

When should I come to the hospital?

Come to the admitting department of Toronto General Hospital 2 days before your surgery date. Please check in before 12:00 pm (noon).

What happens after I arrive?

- You stop taking your Warfarin (Coumadin), new oral anticoagulant such as Rivaroxaban (Xarelto), or blood thinner by needle, such as Tinzaparin (Innohep).
- We start to give you a medicine called Heparin through an intravenous (IV). Your body will need the 2 days before your surgery to reverse the effects of the blood thinner medicine you were taking.

- We may have you do more medical tests. These tests help your surgeon plan your surgery. These tests may include:
 - echocardiogram (ECHO)
 - electrocardiogram (EKG or ECG)
 - CT scan
 - pulmonary angiogram
 - right and left heart catheterization
 - ventilation/perfusion scan (V/Q scan)
 - pulmonary function test (PFT) and arterial blood gases (ABGs)
 - blood work
 - femoral and carotid Doppler ultrasound

You can find more information about some of these tests in the patient brochure: What is Chronic Thromboembolic Pulmonary Hypertension (CTEPH)?

• You speak with your surgeon and other members of your surgical team. They will answer any questions you have, give you more information about the surgery and provide support.

The members of your surgical team include:

- Dr. Marc de Perrot (surgeon)
- Dr. Laura Donahoe (surgeon)
- Anastasia Bykova (nurse practitioner)
- a surgical resident and/or fellow (doctors doing further training)
- Jennifer Monroy (administrative coordinator)
- You have an enema the evening before your surgery so your bowel is empty during your long surgery .
- You are not allowed to eat or drink anything the midnight before your surgery.

What happens on the day of my surgery?

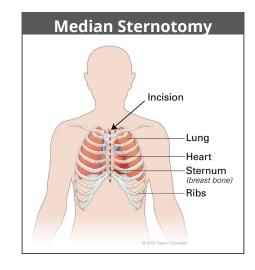
- Your family can visit you before 7:00 am the day of your surgery.
- During your surgery, your family and close friends can wait in the surgical waiting room. This is on the 3rd floor of Toronto General Hospital. There is a volunteer in this area that can provide help if needed.
- Just before your surgery, we ask you to shower using a special (antimicrobial) soap. This will help get rid of any germs on your body.
- Your surgery will take about 7 to 8 hours. During your surgery, a nurse may come out of the operating room to update your family and friends. At the end of your surgery, your surgeon may also come to the waiting room to give them an update.

What happens during my PEA surgery?

- 1. We take you to the operating room and give you an intravenous (IV).
- 2. We give you pain medicine and a medicine to help you relax while doctors put a large intravenous catheter (tube) and arterial catheter into your body.

You then get a medicine called general anesthesia. This makes you sleep through the surgery.

- Your surgeon makes an incision (cut) through your chest bone, called a Median Sternotomy (see the picture to the right). This allows him to reach your heart and major blood vessels.
- Your heart and major blood vessels are connected to a heart-lung bypass machine. The bypass machine takes the blood away from your heart so your surgeon can clearly see the clot in your arteries.

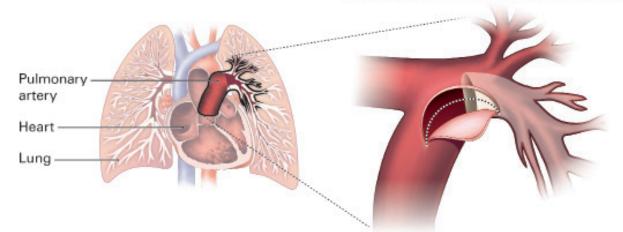


The machine also protects your body by

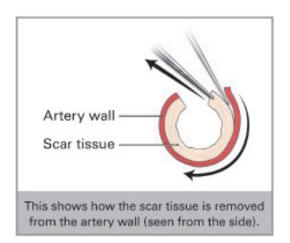
cooling it to half its normal temperature. Once your body is cooled down, the heart-lung bypass machine can be stopped temporarily. This makes it safer to remove the scar tissue from your lung vessels.

- 5. Your surgeon makes incisions in your lung vessels so he can reach the scar tissue. He carefully removes the scar tissue from the inside of the artery walls on both sides of your lungs (see the image below).
- 6. Once he removes the scar tissue, your chest bone is wired back together so it can heal. The wires won't need to be taken out and are safe for your body. They won't cause any problems with metal detectors in an airport.
- 7. After your surgery is done, we move you out of the operating room and continue to give you medicine so you stay asleep overnight.

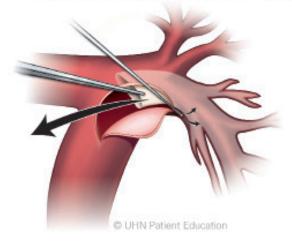
Pulmonary thromboendarterectomy surgery



1. An incision (cut) is made in the pulmonary artery.



The scar tissue is carefully removed from your artery walls with special tools. Then it is pulled out of your lungs through the incision.



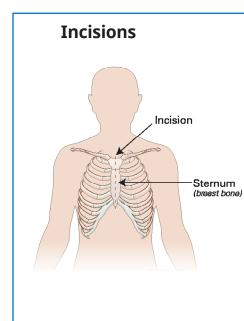
Where will I go after surgery?

After surgery, we move you to the Medical Surgical Intensive Care Unit (MSICU) on the 10th floor or the Cardiovascular Intensive Care Unit (CVICU) on the 2nd floor. You stay there for about 2 to 4 days.

When you wake up, it may seem noisy and busy. This is a normal part of your care. Try to stay calm and don't pull on any tubes.

What can I expect to have on my body?

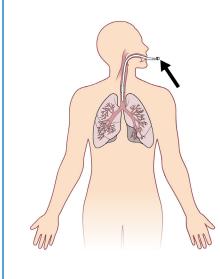
After your surgery, you will have:



You will have an incision called a sternotomy down the middle of your chest. It will be about 20 centimeters (7 to 8 inches) long.

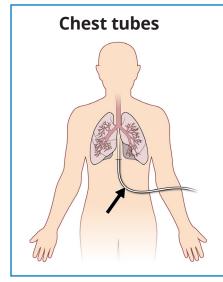
Your surgeon uses dissolvable stitches to close the incision. This means they go away on their own. Bandages will cover your incisions. We remove them 2 days after your surgery.

Endotracheal tube (ETT) and ventilator



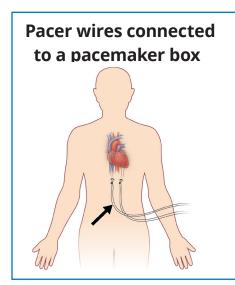
An endotracheal tube is also called a breathing tube. The tube is attached to a ventilator. Together, they help you breathe until your body recovers. We remove the tube when it's safe for you to breathe on your own.

When you first wake up, the breathing tube may make you feel like you are choking. Try to stay calm. You won't be able to talk while you have the tube, but we will give you a writing pad. You will still be able to let us know your needs.



You will have 3 chest tubes coming out of your sides. These tubes remove air and fluid from the inside of your chest area. The tubes are attached to a machine that helps suck the air and fluid out.

We use stitches to keep the chest tubes in place. These are not dissolvable. We remove your chest tubes once it is safe. We remove the stitches 24 hours after we take the tubes out.



You will have pacer wires attached to your heart. These wires are connected to a pacemaker box.

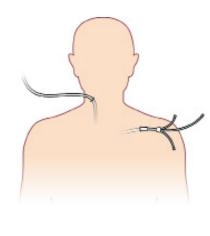
After your surgery, your heart rate may slow down. The pacemaker will use electric current to help your heart beat faster. Once it is safe, we will remove these wires at the same time as your chest tubes.

Intravenous (IV)



You will have one IV line in your arm so we can give you fluids and pain medicines. These medicines will help you relax and manage any pain you may feel.

Central Lines



You will have 2 central lines. One line (like a big IV catheter) will be in the right side of your neck and 1 will be in the upper left side of your chest. We use these lines to give you medicines and take blood samples. We also use them to continuously check your blood pressure on the right side of your heart and pulmonary (lung) artery.

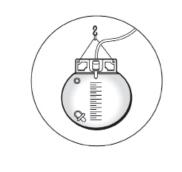
The central line from your neck will come out at the same time as your chest tubes and pacer wires. The central line in your upper chest will come out within 1 week after surgery.

Arterial Lines



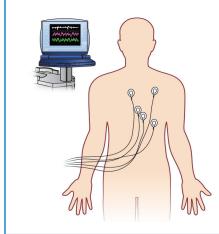
You will have 2 arterial lines. One will be in your wrist and 1 will be in your groin area. These tubes look like your IV, and we use them to take blood samples without having to poke you with needles. They also continuously check your blood pressure.

Urinary catheter



You will have a tube draining your bladder. You have this tube for up to 7 days. While you are in the hospital, the nurse measures how much you urinate (pee).

Heart monitor



We attach you to a heart monitor. This doesn't mean there is a problem with your heart. We do this for all patients who have your type of surgery.

The heart monitor helps us see your vital signs like your heart rate, your blood pressure and how much oxygen is in your blood.

While you are in the MSICU, your body is recovering. When it's safe, we remove your breathing tube and some other tubes or drains and move you from the MSICU.

What happens after I leave the MSICU?

• We move you to the Thoracic Surgery Step-Down Unit (SDU) on 10 Eaton South. There are 4 beds in a SDU room. Both male and female patients are cared for in this room. A thoracic nurse will be in the room with you at all times. You will stay in the SDU for about 2 to 4 days.

- You will still be connected to a heart monitor and may still have some of the tubes you had in the MSICU. You may also need oxygen for a short time as you recover. But, as your health improves the rest of the tubes are removed from your body.
- When you are ready, we move you to a regular ward room on 10 Eaton South until you go home.
- During the rest of your hospital stay, you work closely with a physiotherapist and respiratory therapist. They help you exercise your body and lungs.

How can I manage my pain?

Most patients don't have a lot of pain. After your surgery, we give you pain medicine through your IV to keep you comfortable. Once you are able to eat and drink again, we give you pain medicine pills. We will work with you to help find the best medicine to manage any pain you feel.

It's important to ask your nurse for pain medicine before your pain becomes very bad.

Controlling your pain is important. It will help you rest, move, walk, and do breathing exercises like deep breathing and coughing. These are all important to help you recover. You can find more information about managing your pain in your **My Surgery Guide**.

When will I start taking my medicine again?

You start taking your Warfarin or new oral anticoagulant (for example, Rivaroxaban) after all your tubes and drains are removed.

If you are taking Warfarin, the Thrombosis Clinic or your family doctor will check your bloodwork and adjust your dose after you leave the hospital. They will be responsible for making sure your INR stays between 2.0 to 3.0.

Before you leave the hospital, we will give you a prescription for Warfarin or another type of blood thinner.



Always follow the instructions for taking this medicine. You will need to keep taking your blood thinner for the rest of your life to prevent new blood clots from forming.

To keep information about your blood thinning medicine with you at all times, get a Medic Alert bracelet. You can find an order form at the website: <u>www.medicalert.ca</u> or call 1 800 668 1507.

Discharge checklist

During your hospital stay, we will help you prepare for discharge (going home). Nurses and other health care professionals teach you what you need to know to care for yourself at home.



Make sure you understand all of these before you go home:

- $\hfill\square$ caring for your incision
- □ protecting your breast bone
- \Box showering
- \Box driving
- □ other activities
- $\hfill\square$ new medicines that you started in the hospital
- □ managing your pain
- □ managing your bowels
- $\hfill\square$ eating and drinking
- $\hfill\square$ a follow-up appointment with your surgeon
- □ Warfarin and managing INR (clotting time)
 - The person managing my Warfarin dose is:_____
 - Phone number:_____
 - Discharge dose of Coumadin:_____
 - Date of next INR test:_____

Going home

How can I expect to feel as I recover?

It takes time to heal and recover after any major surgery. Each person recovers at their own pace. You will have good days and bad days.

You may notice your breathing getting a little better after surgery. But, it may take a few weeks to a few months to fully recover. Some patients notice improvements for up to a year after surgery.



Remember: Don't push yourself too much, and give your body time to rest. A good balance between rest and exercise is best to help you recover.

After surgery, you or your family may find changes in your personality such as being easily frustrated or impatient. Another possible change may be having trouble concentrating for a long time. For example, you may not be able to sit through a movie without taking a break. **These changes are temporary and will improve over few weeks**.

After your surgery, you may also have:

Fatigue or trouble sleeping

If you have trouble sleeping after your surgery, take a couple of short naps during the day. Your fatigue (tired feeling) will get better as you heal. Avoid taking naps late in the day because this may cause sleep problems at night.

Mood swings or trouble concentrating

This is common after major surgery. As you continue to heal and return to your normal activities, this should improve.

A poor appetite

After your surgery, you may not feel like eating as much or feel a little sick to your stomach. You may also notice a change in the taste of food.

Your appetite should return to normal over time. Try eating smaller meals more often in the day instead of 3 large meals. You can also try adding a liquid meal replacement, such as Boost or Ensure.

Constipation

Some pain medicines can cause constipation and hard stools (poo). Try to eat more foods that are good sources of fibre, such as fruits and vegetables. If you have a prescription for a stool softener, follow your pharmacist's instructions for taking it.

How do I care for my incision?

Your incision (cut from surgery) may be red, uneven or bumpy. You may notice a small amount of yellowish or bloody fluid leaking from it. You may feel some itching, numbness, tightness or pulling around your incision. All of these are normal.

If you have pain at your incision area, take your pain medicine. Make sure you follow the instructions on your prescription. Holding a soft pillow or rolled-up blanket against your incision when you cough or get up from a bed or chair can help with pain.

When you are home:

- Leaving your incision open to the air will help it heal.
- Don't use perfumes, creams or powders on your incision (unless your surgeon or your nurse practitioner gave you different instructions).
- Don't take a bath, swim or use a hot tub until your incision is fully healed and you have talked with your surgeon or your nurse practitioner.
- Use mild soap and don't spray directly on your incision when you shower.
- Don't scratch, scrub or rub your incision.
- Wear loose fitting cotton shirts. This will help keep material from rubbing against and irritating your incision.
- Some women may feel the weight of their breasts pulling on their incision. Wearing a bra can help. Try padding the area where the bra touches your incision to prevent rubbing.

Follow these instructions for protecting your breast bone:

- Don't lift more than 5 pounds (about 2 kilograms) for 12 weeks.
- If you didn't get information about protecting your breast bone called sternal precautions, talk to any member of your health care team.

🄏 What activities can I do when I go home?

You can start doing mild exercise after your surgery. Walking is a very good exercise to do after your surgery. Slowly start to exercise more often and for a longer time. Don't lift weights or do any exercises that could injure your breast bone.

Remember to rest after your exercise or activities. You will have more energy after you rest. Be patient. The amount you can do each day or week will improve with time.

A list of some activities you can do:

✓ showering and dressing

Using a shower chair for the first 2 weeks may help. Make sure someone is at home with you when you have a shower in case you slip.

- ✓ washing dishes
- ✓ dusting furniture
- ✓ sweeping the floor
- ✓ going up and down stairs
- ✓ (unless your surgeon gave you different instructions)
- ✓ peeling vegetables
- ✓ short walks every day



No. You can't drive until your breast bone is completely healed. Unless your surgeon gives you different instructions, you can ride as a passenger as long as you wear a seatbelt. Your surgeon will talk to you about when you can drive again during your clinic visits.

You should expect to be off work for at least 3 months after your surgery. We will talk more with you at your clinic visits to decide when you can return to work.

What about sex?

Wait 6 weeks after your surgery before you have sex. When you can climb 2 flights of stairs comfortably, you are probably ready to have sex.

Choose positions that won't stress, irritate, or put pressure on your incision. Stop if you have pain, shortness of breath or feel dizzy.

What problems should I look out for?

Go to your nearest emergency room or call 911 if you:

- have trouble breathing
- are bleeding
- have chest pain
- fainted

Call your family doctor or your surgeon's office right away if you:

- have new redness, warmth or swelling around your incision
- have an unusual smell, liquid or pus (thicker yellowish or white liquid) coming from your incision
- feel increasing pain at your incision
- have a fever **higher** than 38.5° C or 101° F
- see your incision has opened up
- feel your heart beating faster or in a different way
- feel dizzy or like you will faint
- have swelling in a leg or both legs
- have shortness of breath that is getting worse
- cough up yellow or green mucous with a bad smell
- cough up fresh blood

The phone number of your surgeon's office is 416 340 4800 ext 5274.

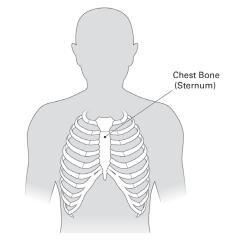
You can find more information about Chronic Thromboembolic Pulmonary Hypertension in the patient brochure: **What is Chronic Thromboembolic Pulmonary Hypertension (CTEPH)?**

Moving after a sternotomy and pulmonary endarterectomy surgery

During your surgery, the bone at the centre of your chest (known as your sternum) was cut. **It can take up to 12 weeks to heal**.

It is important to protect your chest while your sternum is healing.

- Moving after your surgery will help with your breathing, healing and discomfort.
- Make sure you are moving your body without it hurting.
- STOP what you are doing if you hear any clicking at your chest or feel a lot of pain (more than usual) at the incision site.



Sternal precautions:

(Instructions to follow for the first 6 to 8 weeks after surgery)

- When coughing or sneezing: Hold and gently squeeze a pillow against your chest bone.
- When getting in or out of bed: Use the "log-roll" method. Do not reach for hand rails. Instead, use your legs to help you roll onto your side, bring your legs off the bed, and use your elbow to push yourself into the bed, bringing your upper body upright.
- When standing up from sitting: Cross your arms over your chest and lean forward. Use your legs to push you up.
- When lifting, pushing or pulling: Keep your elbows and upper arms close to your body.
- When reaching over your head: Move both arms at the same time and do so in a pain free range.



- When standing from a chair: Lean forward and gather momentum to bring your body upright. Be sure family and friends don't pull on your arm to help you stand.
- When going up or down stairs: Be sure you are placing no more than 10 pounds (5 kilograms) on the handrail.
- When lifting objects lighter than 5 lbs: Keep your elbows close to your body, or ask for help.
- Do not lift objects heavier than 5 lbs.
- When opening heavy doors: Use your body to push the door open. Keep your elbows close to your body when pulling the door open.
- When putting on your bra: Tie the clasps in front of your body. Then turn the bra around and place your arms through the straps to avoid having to reach behind you.
- When riding in a car: Place a pillow or rolled towel between your chest and the seat belt. Always wear your seat belt.
- Avoid wearing backpacks.
- Keep your back straight when you stand and sit. Do not slouch.
- **Consider using** a bath chair and hand held shower when you bathe. Use a raised toilet seat over your toilet to help with sitting, standing and doing transfers.

Who do I call if I have questions or need more information?

Toronto CTEPH Program

Division of Thoracic Surgery – 9N 921 Toronto General Hospital 200 Elizabeth Street Toronto, ON M5G 2C4 Phone: 416 340 4800 extension 5274 Fax: 416 340 3610

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