

Empower

Understand

Thrive



EMPOWER
MY CONGENITAL HEART



My Heart, My Journey:

An Empowered

**Approach to CHD
Procedures**

Types of Cardiac Procedures

2/14

While cardiac procedures can take many forms, this guide focuses on procedures such as **heart catheterizations and surgeries**.

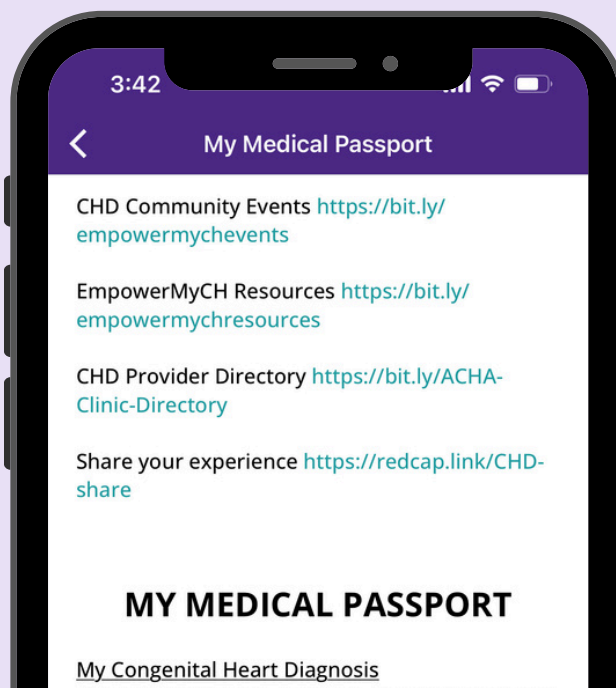
Examples of other tests or heart procedures not covered in this guide include:

- ◆ **Electrocardiogram** (ECG or EKG)
- ◆ **Echocardiogram** (Echo)
- ◆ **CT/MRI**
- ◆ **Stress tests**

If you would like to learn more about the heart procedures not included in the following pages, you can open your Medical Passport in the EmpowerMyCH app and click on the “**EmpowerMyCH Resources**” link, or visit our website.



Resource: Empower My Congenital Heart website
bit.ly/EmpowerMyCHResources



Types of Cardiac Procedures

Getting ready for a heart procedure can help you feel more confident, lower your stress, and support a better recovery.

This guide will help you understand what questions to ask, whom to ask, and why asking matters.

Ensuring Specialized Care

If your doctor has recommended a heart procedure, the first step is to see if you can discuss it with an **Adult Congenital Heart Disease (ACHD) specialist**—a cardiologist with expertise in congenital heart conditions.

Most cardiologists are **NOT** ACHD specialists; confirm their board certification or ACHD expertise. If you have any procedure, ask whether the specialist is an ACHD/CHD cardiologist or surgeon. It is the most important thing you can do.



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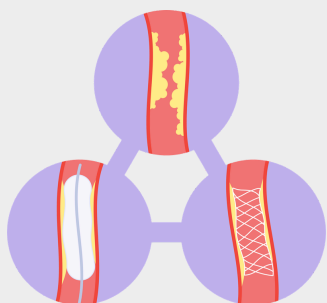
Lindsay Alano, Heart & Liver Transplant Recipient (Former CHD Patient)

“Don't be afraid to seek a 2nd or 3rd opinion. You are your best advocate.”

Types of Cardiac Procedures

Catheter Procedures:

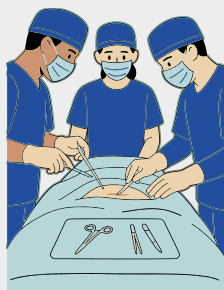
A thin tube (catheter) is inserted into a blood vessel and guided to the heart to check for problems or treat them.



- ◆ Shorter recovery (few days to weeks)
- ◆ Typically same-day discharge or short hospital stay (1–2 days)

Heart Surgery:

A major surgery in which doctors repair or replace damaged heart structures. It may be open-heart surgery or a less invasive surgery.



- ◆ Longer recovery (weeks to months)
- ◆ Longer hospital stay (several days to weeks)



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Anushree Agarwal, MD, MAS
ACHD Cardiologist

“ Just because a center specializes in ACHD doesn’t mean they have the best surgeon for your condition—getting the right second opinion can be crucial. ”



Catheter vs. Surgical Treatment

Sometimes, your doctors may offer you two treatment options: a **cath-based procedure** or **open-heart surgery**. Choosing between them can be a complex decision. Here are some general considerations your doctors might keep in mind before recommending one option over the other.

Technical Challenges

- ◆ How the different parts of your heart are connected.
- ◆ How any previous surgeries or repairs could affect which treatments are possible.
- ◆ The size of the valve or hole that needs to be treated.

Risks vs. Benefits

Even if it's technically feasible to do both, a cath or open-heart procedure, sometimes the risks of one might be greater.

Long-Term Outcomes

Even though recovery can take longer, a surgical procedure may sometimes lead to better long-term results, such as needing fewer surgeries in the future.

Experience or Expertise

Some doctors or hospitals may have more experience with one type of procedure than another.

Cath-Based Procedures



Plumbing Issues

“Structural & Vascular Issues”

Cath-based procedures, often referred to as **left- or right-heart catheterization**, can be used to diagnose and treat structural and vascular issues.

Diagnosis

- ◆ Oxygen levels and pressures inside the heart may be measured.
- ◆ Blood flow through the heart and blood vessels may be checked.

Treatment

- ◆ **Closing Holes in the Heart:** Such as atrial septal defects (ASD) or ventricular septal defects (VSD).
- ◆ **Treating Valve Problems:** Some procedures help repair or replace heart valves. Other options include using a balloon to open a narrowed valve.
- ◆ **Improving Blood Flow:** Uses a balloon or stent to open a narrowed artery. This can be done in arteries like the coronary, pulmonary, or aorta.
- ◆ **Closing Abnormal Blood Vessels:** Can include coiling or closing off an abnormal blood vessel, such as a collateral or a fistula.

Cath-Based Procedures



Heart Rhythm Issues

“Electrical Issues”

Cath-based procedures can also be used to diagnose and treat heart rhythm issues.

Diagnosis

Electrophysiology Study (EP Study)

A cath-based procedure that identifies abnormal heart rhythms, determines their origin, and helps guide treatment.

Treatment

- ◆ **Ablation** is usually performed during an EP study and uses energy to treat the area causing abnormal heart rhythms.
- ◆ **Pacemakers** stimulate the heart as needed to keep it beating regularly.
- ◆ **Implantable Cardioverter Defibrillator (ICD) placement** prevents life-threatening arrhythmias.



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Lindsay Alano, Heart & Liver Transplant Recipient (Former CHD Patient)

“Connecting with someone of similar gender/condition who had the procedure at the same hospital was invaluable.”



Surgical Procedures

Open-Heart Surgery

This involves making an incision in the chest and using a heart-lung machine to support circulation while the heart is repaired. It is typically required for:

- ◆ **Valve repairs or replacements**
- ◆ **Repair or reconstruction of CHD**
- ◆ **Heart transplantation**

Minimally Invasive Approaches

These procedures use smaller incisions to reduce recovery time and complications. Examples include:

- ◆ Minimally invasive valve surgeries
- ◆ Pacemaker and ICD (*implantable cardioverter defibrillator*) placement



CLINICIAN EMPOWERMENT

Jennifer Gilmartin, ACHD
Nurse Practitioner

“Your dental care may need to be postponed following a procedure; many patients have to wait 6 months after a procedure.”

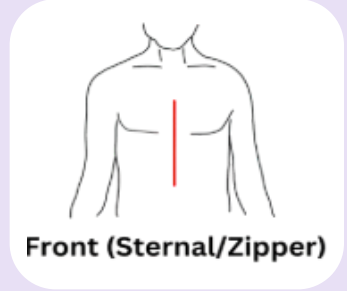


Types of Surgical Approaches

Sternotomy

“Traditional Zipper”

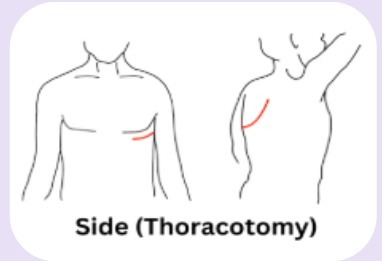
A sternotomy is when the surgeon makes an incision down the center of the chest and opens the breastbone (sternum) to reach the heart. A sternotomy is used for heart surgeries that need full access to the heart and major blood vessels.



Thoracotomy

“Side Chest Approach”

A **thoracotomy** is when the surgeon makes an incision on the side of the chest, **between the ribs**, instead of opening the breastbone (sternum). This approach may be used when full access to the entire heart is not needed. In some cases, a thoracotomy can be part of the minimally invasive procedure.



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Karla Deal, Patient with Tetralogy of Fallot

“If you have young children, consider reading books like *My Scar is Beautiful* to prepare them.”

🔍 Questions For Your Cardiology & Surgical Team

- ◆ Why is this procedure necessary?
- ◆ What are the expected benefits?
- ◆ Are there alternative treatment options?
- ◆ What will happen during the procedure, and how long will it take?
- ◆ What are the possible risks and complications?
- ◆ How should I prepare for the procedure (fasting, medications, tests)?



CLINICIAN EMPOWERMENT

Dr. Kimberly Payton, EdD,
Patient Parent & Advocate

“Using a notebook to write down your questions and thoughts before the visit as well as during your visit with your medical provider can help to reduce stress, anxiety and empower patients to feel a part of the care and treatment process.”



PEER EMPOWERMENT

Ana Cecilia Gonzalez, *Patient with Transposition, Double Inlet Left Ventricle*

“It is very important to feel your doctor is listening to your concerns. Trust is key, and good communication makes the process easier.”

? Questions For Your Healthcare Team

Social Workers, Case Managers,
Counselors, or Patient Services

- ◆ How long will I stay in the hospital, and will I need help after discharge?
- ◆ What are the lodging, parking, and food options for my family?
- ◆ What should I bring to the hospital?
- ◆ What mental health or emotional support resources are available?
- ◆ Can I connect with a peer mentor or spiritual services?
- ◆ Is there a social worker who can help with finances, transportation, and insurance?



PEER EMPOWERMENT

Ana Cecilia Gonzalez, Patient with Transposition, Double Inlet Left Ventricle

“It’s okay to feel afraid; expressing it helps with coping. Make sure to ask all your questions, even basic ones.”



PEER EMPOWERMENT

Joe Valente, Patient with Tetralogy of Fallot

“Speaking to a psychiatrist beforehand helped me with emotional recovery in the post-op period.”



Tips from Peers



PEER EMPOWERMENT

Savannah Regan-Hendrix,
Patient with Transposition

“ It may not come to mind, but ask your medical team for advice on navigating physical intimacy with yourself and/or partners after surgery and maintaining connection in new ways. ”



PEER EMPOWERMENT

Lindsay Alano, *Heart & Liver Transplant Recipient (Former CHD Patient)*

“ Understanding what milestones must be met for discharge from the hospital helped set expectations. ”



PEER EMPOWERMENT

Joe Valente, *Patient with Tetralogy of Fallot*

“ Have someone in your family take notes during your surgery and acute post-op period so you have a record of what happened. ”



If you would like more ideas for questions to ask your care team, visit

Conquering CHD at:
bit.ly/achd-questions



Practical Tips for Your Hospital Stay



PEER EMPOWERMENT

Joe Valente, Patient with Tetralogy of Fallot

“Bring noise-canceling headphones and have a playlist of music for different moods, including one for relaxation and pain.”

Personal Items to Bring

- ◆ Comfortable button-up shirts for easy dressing. After a sternotomy, pullover shirts can be hard to put on.
- ◆ Toiletries (soap, shampoo, or toothbrush) and personal care items.
- ◆ Headphones, books, or entertainment.
- ◆ List of medications and emergency contacts.
- ◆ Chargers for devices

For Women:



PEER EMPOWERMENT

Savannah Regan-Hendrix, Patient with Transposition

“Bring extra menstrual items for comfort in case you get your period during your hospital stay. Hospital-provided menstrual products may not be the most comfortable for you.”



Practical Tips for Your Hospital Stay



PEER EMPOWERMENT

Ana Cecilia Gonzalez, Patient with Transposition, Double Inlet Left Ventricle

“Ask for spiritual help (a Chaplin) for support and guidance if you need it.”

Personal Touches for Your Hospital Room

- ◆ Put up pictures of your family, friends, or pets.
- ◆ Blankets, or small comforts from home.
- ◆ Music or relaxation aids to reduce stress
- ◆ Decorate with posters, drawings, or cards from friends

For Women:



CLINICIAN EMPOWERMENT

Jennifer Gilmartin, ACHD Nurse Practitioner

“For those who typically wear breast/chest supporting garments and are scheduled to undergo a mid-sternal incision, consider bringing comfortable, supportive garments with front closures.”