

Empower

Understand

Thrive



EMPOWER

MY CONGENITAL HEART



Championing My Health

**From Awareness to
Action in Symptom
Management**

Know When to Call, Know When to Go

When you are not feeling well, deciding whether to go to the emergency department (ED) or call your CHD cardiologist can be difficult. The chart on the next page can help guide your decision, but here are some general rules to keep in mind:



Urgent

If your symptoms are **sudden, severe, or worrisome, go to the nearest ED or call 911.**

Provide the contact information for your CHD cardiologist. They can assist with your care and help determine if a transfer is needed.

Choose to be driven to your CHD center ED, bypassing the nearest ED if your symptoms are worsening from your baseline—but you are otherwise feeling stable.

*You may hear both **Emergency Department (ED)** and **Emergency Room (ER)** used when talking about emergency care. They are the same thing.*

Know When to Call, Know When to Go

Non-Urgent

If you decide to contact your **CHD clinic**, you might not get a response for a few days.

Unsure

If you are unsure about the urgency, call the CHD center and ask for the on-call CHD cardiologist. Most **CHD centers** have an **on-call CHD cardiologist available 24/7** to answer questions.



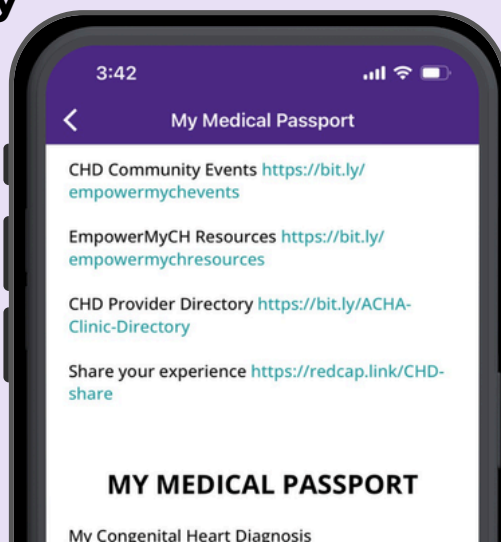
PEER EMPOWERMENT

Karla Deal, Patient with Tetralogy of Fallot

“When deciding whether to go to the emergency room, I call my cardiologist while on the way to discuss the situation. If my cardiologist says I don't need to go, I simply turn around. This way, I'm already en route if I **do** need to be seen.”

Provider Directory

You can also find ACHD cardiologists on the **My Medical Passport** page of your EmpowerMyCH app.





Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Severe shortness of breath that happens suddenly or gets worse quickly.
- ◆ Trouble breathing at rest (even when sitting or lying still).
- ◆ Chest pain, pressure, or tightness, along with shortness of breath.
- ◆ Bluish lips, face, or fingertips (signs of low oxygen) that are different or worse from your baseline.
- ◆ Feeling dizzy, fainting, or confusion with breathing trouble.
- ◆ Coughing up pink or foamy mucus (sign of fluid in the lungs).



Contact Your Cardiologist Promptly If You Have:

- ◆ Gradual worsening of shortness of breath over days or weeks.
- ◆ Increased difficulty breathing during baseline activities (e.g., walking short distances, climbing stairs).
- ◆ Needing more pillows to sleep or waking up gasping for air.
- ◆ New or worsening swelling in the feet, legs, or stomach, along with shortness of breath.



Monitor at Home (Call if Symptoms Persist or Worsen)

- ◆ Mild shortness of breath that happens only with exercise but improves with rest.
- ◆ Temporary shortness of breath due to anxiety or a mild cold, but no other concerning symptoms.



CLINICIAN EMPOWERMENT

Mark Norris, MD, MS
ACHD Cardiologist

“ We recommend adding our 24/7 contact number to your emergency medical information. You can store it in your smartphone's emergency medical info, which can be accessed without a passcode, or link it to a medical alert bracelet. Most patients find their smartphones the easiest option.”



Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Sudden, severe, or crushing chest pain that lasts more than a few minutes.
- ◆ Pain that spreads to your jaw, neck, back, arms, or shoulders.
- ◆ Chest pain with shortness of breath, dizziness, fainting, or nausea.
- ◆ A heavy, tight, or squeezing feeling in your chest.
- ◆ Cold sweats or paleness, along with chest pain.



Contact Your Cardiologist Promptly If You Have:

- ◆ Mild or moderate chest pain that comes and goes but feels different than your baseline.
- ◆ Pain that happens with activity and improves with rest.
- ◆ New or increasing chest discomfort, even if it's not severe.
- ◆ A burning sensation that doesn't improve with antacids.

Triage Guide

Chest Pain or Chest Tightness



Monitor at Home (Call if Symptoms Persist or Worsen)

- ◆ Brief, mild chest discomfort that lasts seconds and doesn't return.
- ◆ Pain that is clearly related to muscle strain or posture.
- ◆ Chest pain that improves with deep breathing or a change in position.



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If you're unsure, call your doctor—chest pain in CHD patients should never be ignored.

It's always safer to call your doctor for guidance. CHD patients are at higher risk for serious complications, so don't ignore symptoms that feel unusual or worsening.



Seek Emergency Care

(Call 911 or go to the ER) If You Have:

- ◆ Sudden, fast, or irregular heartbeats that won't stop.
- ◆ Palpitations with chest pain, shortness of breath, dizziness, or fainting.
- ◆ A very slow heart rate (bradycardia) with weakness or confusion.
- ◆ A racing heart (tachycardia) over 150 beats per minute at rest.



Contact Your Cardiologist

Promptly If You Have:

- ◆ Frequent palpitations that last more than a few minutes.
- ◆ A fluttering or pounding heart that happens at rest.
- ◆ New or worsening palpitations, especially if they feel different than your baseline.
- ◆ Heart skipping beats regularly or feeling like it stops and starts.



Monitor at Home (Call if Symptoms Persist or Worsen)

- ◆ Occasional brief palpitations that last only a few seconds.
- ◆ Palpitations caused by stress, caffeine, dehydration, or lack of sleep.
- ◆ A single skipped beat that doesn't repeat.



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If palpitations feel unusual or keep happening, talk to your cardiologist—they could be a sign of an underlying heart issue in CHD patients.



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Can my medications affect my heart rate?

Yes, they can. Ask your adult congenital cardiologist what your baseline heart rate should be.



Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Sudden or severe lightheadedness that does not go away.
- ◆ Feeling like you are about to faint or actually passing out (syncope).
- ◆ Lightheadedness with chest pain, shortness of breath, or irregular heartbeat.
- ◆ Weakness on one side of the body, slurred speech, or confusion (possible stroke signs).
- ◆ A very slow (bradycardia) or very fast (tachycardia) heart rate.



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If you have frequent lightheadedness, talk to your cardiologist—it could be a sign of a heart rhythm problem, low blood pressure, or other serious issues.



Contact Your Cardiologist Promptly If You Have:

- ◆ Frequent or recurring lightheadedness that is new or different.
- ◆ Feeling dizzy when standing up (possible low blood pressure issue).
- ◆ Episodes of near-fainting, even if brief.
- ◆ Lightheadedness with palpitations or mild shortness of breath.
- ◆ Recent medication changes that could be affecting blood pressure or heart rate.



Monitor at Home (Call if Symptoms Persist or Worsen)

- ◆ Occasional brief dizziness that resolves quickly when sitting or resting.
- ◆ Mild lightheadedness from dehydration, standing up too fast, or low blood sugar.
- ◆ Symptoms that improve with fluids, food, or rest.



Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Rapid or severe swelling (in legs, belly, or lungs) that comes on quickly, especially if it's accompanied by shortness of breath, trouble breathing, or coughing.
- ◆ Fast or irregular heartbeats, chest pain, or fainting.
- ◆ Sudden weight gain (e.g., 2-3 pounds in one day or >5 pounds in a week) due to fluid.
- ◆ Blue lips or skin that is new or worse from your baseline, or if you feel very weak and can't catch your breath.



Contact Your Cardiologist Promptly If You Have:

- ◆ Slow weight gain or mild swelling over time, especially if it's stable.
- ◆ Mild swelling that doesn't seem to get worse.
- ◆ Other signs like feeling tired, or having trouble breathing with minor exertion.
- ◆ Recent medication changes (e.g., changes in diuretics or other heart medications).



Monitor at Home

(Call if Symptoms Persist or Worsen)

- ◆ Mild swelling in feet or legs that stays the same or gets better with rest.
- ◆ Gradual weight gain without shortness of breath or other serious symptoms.
- ◆ Symptoms that improve with fluids, food, or rest.

If you are noticing frequent swelling or weight gain, let your doctor know—these could be signs of fluid buildup or heart function changes that need attention.



Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Severe fatigue that suddenly worsens or doesn't improve with rest.
- ◆ Exercise intolerance, in which even light activity can cause shortness of breath, chest pain, or dizziness.
- ◆ Fainting or near-fainting episodes during or after exercise.
- ◆ Swelling in the legs, abdomen, or other parts of the body with worsening fatigue.
- ◆ Rapid or irregular heartbeats, or a very slow heart rate, with fatigue.



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If you notice that your level of activity is gradually (e.g., over months or years) or suddenly decreasing from your baseline, let your doctors know. Provide specific examples of how your exercise level has changed (e.g., "I was able to walk up 2 stairs of flight until 2 months ago, but now even going up one flight of stairs is difficult"). This will help your doctor get to the bottom of your problems more effectively.



Contact Your Cardiologist Promptly If You Have:

- ◆ New or worsening fatigue with mild or moderate activity that isn't normal for you.
- ◆ Exercise intolerance that has been getting worse over time.
- ◆ Shortness of breath or mild chest discomfort that occurs after exertion.
- ◆ Feeling unusually tired or weak with daily tasks, even without exercise.
- ◆ Recent medication changes that may be affecting energy levels or heart function.



Monitor at Home (Call if Symptoms Persist or Worsen)

- ◆ Mild fatigue that resolves with rest and doesn't interfere with daily activities.
- ◆ Exercise intolerance that improves over time with gradual activity.
- ◆ Temporary tiredness after moderate exercise, which gets better with proper rest and hydration.



Seek Emergency Care (Call 911 or go to the ER) If You Have:

- ◆ Fever of 100.4°F (38.0°C) or higher along with severe symptoms like:
 - ◆ Chest pain or trouble breathing.
 - ◆ Confusion, dizziness, or fainting.
 - ◆ Fast or irregular heartbeat that doesn't improve.
 - ◆ Severe headache with a stiff neck.
 - ◆ Fever that does not respond to medications like Tylenol.
- ◆ Fever with shaking chills (could be a sign of a serious infection like endocarditis).

IMPORTANT



CHD patients have a higher risk of serious infections of the heart tissue, called endocarditis. If you have a fever, advocate for a blood culture before taking antibiotics. A blood culture may be needed to detect infection before starting treatment. If you have any doubts, please call your CHD cardiologist for guidance.

Why? Taking antibiotics first can make it harder to find the right treatment by making your blood test results unclear.



Contact Your Cardiologist Promptly If You Have:

- ◆ Fever of 100.4°F (38.0°C) or higher lasting more than 24 - 48 hours.
- ◆ Night sweats, chills, or flu-like symptoms that don't improve.
- ◆ Fever with new or unusual pain (e.g., burning when urinating, persistent cough, skin redness/swelling).
- ◆ Fever that comes and goes for days or weeks with no clear cause.



Monitor at Home

(Call if Symptoms Persist or Worsen)

- ◆ Mild fever (below 100.4°F / 38.0°C) with no other concerning symptoms.
- ◆ Fever from a known minor illness (e.g., common cold) that improves within a day or two.
- ◆ Fever that goes away with rest, fluids, and fever-reducing medicine (Tylenol or Ibuprofen).

Baseline Overview

Knowing your baseline health information helps you act confidently when seeking care for your symptoms.

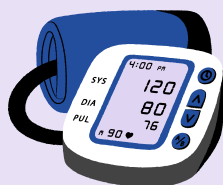
What should I know?

- ◆ Your baseline health information (see below)
- ◆ Your cardiologist's contact information (Name, Phone Number)

My Baseline Health Information

- ◆ Your complete medical history (Digital Medical Passport)
- ◆ Blood Pressure Measurements
- ◆ Oxygen Levels (oxygen saturation)
- ◆ Heart Rate
- ◆ Levels of Activity (how active I am at baseline before feeling symptoms)
- ◆ Medications

Blood Pressure



Blood pressure (BP) is the amount of force your blood uses to get through your arteries.

How to check your blood pressure:

- ◆ Rest your arm at chest height, support your back, and keep your feet flat on the floor.
- ◆ Take at least two readings, 1-2 minutes apart.
- ◆ If you have a Bluetooth-enabled blood pressure cuff, you can connect it to your phone to automatically log and save your data.

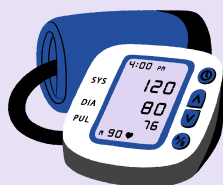


Resource: Learn more at [cdc.gov/bloodpressure](https://www.cdc.gov/bloodpressure)

Why is it important to maintain a log of my blood pressure?

- ◆ High blood pressure is a major risk factor for heart attack, stroke, heart failure, brain aneurysms, kidney disease, etc.
- ◆ Low blood pressure can be a sign of decreased function.

Blood Pressure



Some special considerations if you have:

- ◆ Coarctation of Aorta (CoA)
- ◆ Prior surgery on your aorta
- ◆ A shunt surgery (e.g., BT shunt)

Your BP readings likely differ between your **left and right arms**. In that case, the arm with the higher number is most reliable and should be used for regular BP monitoring.

If you have a CoA, check your BP in both upper arms and thighs at least once (preferably at a doctor's office).

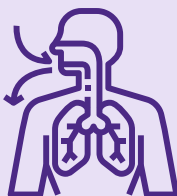
If your BP is higher in your arm, note the difference. It is an important data point that can be followed over time.

Which is more accurate: A wrist BP cuff or an arm BP cuff?



An **arm BP cuff** is always the more accurate choice. BP readings from your wrist are sometimes inaccurate and, therefore, not reliable.

Oxygen Levels



Importance of Baseline

Establishing your **baseline oxygen level** will help you manage your CHD care. If you experience a decrease in your baseline, it could be due to several reasons:

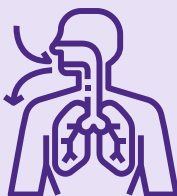
- ◆ Decreased heart function
- ◆ Low hemoglobin
- ◆ Blockage in the arteries
- ◆ Lung problems
- ◆ Inaccurate readings

What is a Normal Oxygen Level?

Each CHD patient is unique. Below is the normal oxygen level range for the general population. It is important to know **YOUR** normal.

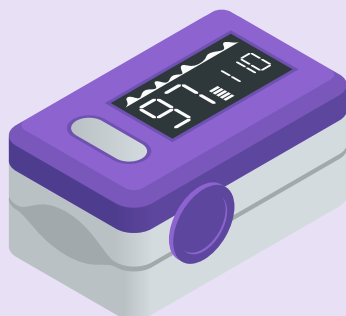
- ◆ **Normal for General Population:** More than 95%
- ◆ **Some CHD Patients:** Long-term oxygen saturation may be below 95%, ranging from 80-95%, depending on how your heart works following surgery.
 - ◆ For some CHD patients, oxygen saturation may be lower (75-85%) at baseline. This can make the skin or lips look slightly bluish, a condition called cyanosis.

Oxygen Levels



Checking Your Oxygen Level

- ◆ Purchase a pulse oximeter (Walgreens, CVS, or online).
- ◆ Place the probe on your index finger.
- ◆ Wait a few seconds for the proper reading.



Inconsistent Readings?

- ◆ Poor circulation.
- ◆ Dark skin pigmentation or thick skin.
- ◆ Tobacco use.
- ◆ Cool skin temperature.
- ◆ Dark fingernail polish, artificial nails, or fingers are not clean.

Heart Rate (HR)

Baseline HR

Your heart rate (HR) is the number of times your heart beats per minute.

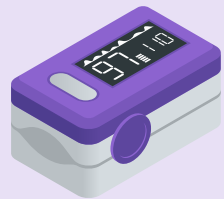
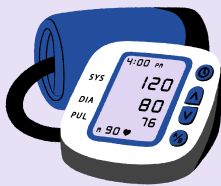
- ◆ **Normal:** 60 - 100 beats/min
- ◆ **Bradycardia** (Low HR): <60 beats/min
- ◆ **Tachycardia** (High HR): >100 beats/min

Checking HR

You can check your heart rate (HR) in several ways.

Devices

- ◆ Wearable Devices (i.e., Apple watches, FitBit, etc.)
- ◆ Blood Pressure Machines
- ◆ Pulse Oximeter



Manually

- ◆ Take your pulse on the inside of your wrist, on the thumb side.
- ◆ Use the tips of your first two fingers (not your thumb) and press lightly over the artery.
- ◆ Count your pulse for **30 seconds** and **multiply by 2** to find your beats per minute.

Activity Levels

Identify the level of activity you can perform before feeling tired or short of breath as your **baseline**.

Low Intensity

Examples: Casual walking, laundry, and house chores.

- ◆ No noticeable effect on breathing or heart rate.
- ◆ It is easy to carry on a conversation or sing without pausing for breath.

Moderate Intensity

Examples: Fast walking, water aerobics, dancing (ballroom or social), gardening, and slow cycling.

- ◆ You can talk but can't sing.
- ◆ Your heart rate is at 50-60% of your maximum heart rate.

High Intensity

Examples: Hiking uphill or with a heavy backpack, running, swimming laps, Zumba, heavy yard work, fast cycling, and jumping rope.

- ◆ You can say a few words, but you can't hold a conversation.
- ◆ Your heart rate is at 70-80% of your maximum heart rate.

Effectively Communicate with Your Cardiologist



Make use of the **STARS method** to keep track of all your symptoms in preparation to discuss with your adult congenital cardiologist. This could help your cardiologist better address your needs.

S **Specifics:** location, what may have caused the symptom, etc.

T **Time:** duration, frequency.

A **Associated symptoms:** symptoms occurring with your main symptom.

R **Related factors:** triggers such as coffee or stress, alleviating factors.

S **Severity:** pain scale, impact on daily life.

Keep your discussion focused by covering your main questions and concerns, your symptoms, and how they impact your life. Share any new medications or new activities you're doing.

Ask for clarification if you don't understand what you have been told or if you still have questions. Ask for explanations of treatment goals and side effects.