



**Championing My Health:
From Awareness to
Action in Symptom
Management**

Empower. Understand. Thrive.

Sarah started to notice that she is gradually getting more short of breath with her usual activities. Two months ago, she was able to go up 2 flight of stairs with no problem. But now, she has to stop several times while doing the same thing. What should Sarah do?

- A) Ignore it since everyone gets winded sometimes.
- B) Contact her doctor as it could be a sign of a change in her heart function.
- C) Continue resting and hope it gets better on its own.
- D) Increase physical activity so she can get used to the shortness of breath.

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CORRECT ANSWER B

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 Departments (EDs)** and **ER (Emergency Room)** 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**, getting a response might take 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.



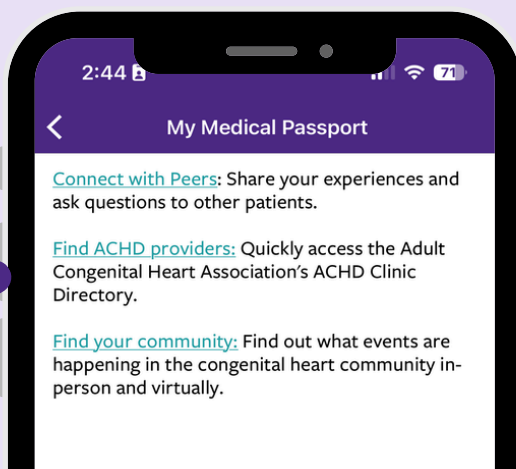
PEER-EMPOWERMENT

Karla Deal - Tetralogy Patient

“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 Link

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



Shortness of Breath or Difficulty Breathing in CHD Patients



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 feet, legs, or stomach, along with shortness of breath.

Shortness of Breath or Difficulty Breathing in CHD Patients

✓ 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.



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. ”

Chest Pain or Chest Tightness in CHD Patients

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.

Chest Pain or Chest Tightness in CHD Patients

✓ 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.

EMPOWERMENT

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.

Palpitations in CHD Patients

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.

Palpitations in CHD Patients

✓ 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.

EMPOWERMENT

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

EMPOWERMENT

Can my medications affect my heart rate?

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

Lightheadedness or Presyncope in CHD Patients



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.

EMPOWERMENT

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.

Lightheadedness or Presyncope in CHD Patients

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.

Edema or Weight Gain in CHD Patients



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).

Edema or Weight Gain in CHD Patients

✓ 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.

Exercise Intolerance or Fatigue in CHD Patients

 **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 where even light activity causes 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 very slow heart rate with fatigue.

EMPOWERMENT

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 more effectively get to the bottom of your problems.

Exercise Intolerance or Fatigue in CHD Patients

⚠ 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.

Bob is a 45-year-old man who has a congenital heart defect which was repaired when he was 7 years old. He has been having a fever with a temperature of 101 °F. He took Tylenol that improved his fever but then it came back again. He was unsure if this could be related to his heart.

Which of the following symptoms should Bob consider as a warning sign and reach out to his doctor?

- A) If it is associated with trouble breathing, chest pain
- B) If it lasts for less than a day
- C) If it is associated with runny nose, congestion
- D) If it resolved with Tylenol and rest

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- C) If it is associated with runny nose, congestion
- D) If it resolved with Tylenol and rest

CORRECT ANSWER A

Fever in CHD Patients

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 as endocarditis. If you have a fever, advocate to have a blood culture done before taking antibiotics. A blood culture test may be needed to check for infection before starting treatment. If in doubt, 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.

Fever in CHD Patients

⚠ 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): It 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 blue-tooth enabled blood pressure cuff, you can connect it to your phone to automatically log and save your data.
- 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) or
- Prior surgery on your aorta or
- A shunt surgery (e.g. BT shunt)

It is **likely** that your BP readings are **different** in your **left and right arms**. In that case, the arm that gives the higher number is most reliable, and should be used for regular monitoring of your BP.

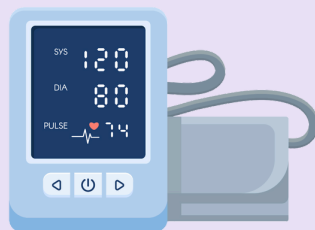
If you have CoA, check your BP in both upper arms and thighs at least one time (preferably at a doctor's office).

If your BP is higher in your arm, know how much the difference is. 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 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 public. It is important to know **YOUR** normal.

- **Normal:** Greater than 95%
- **Some CHD Patients:** long-term oxygen saturation may be below 95%, ranging from 80-95%, depending on how their heart works following previous surgery.
 - For some CHD patients, it could be 75-85% at baseline. This can make the skin or lips look a little bluish, which is called cyanosis.