



How to Talk to Adults with Congenital Heart Defects About Lifelong Cardiac Care

People with congenital heart defects need lifelong congenital cardiac care — but many of them aren't getting it.

You have a unique touchpoint with these patients, whether they're in the emergency room because of their heart problem or for another reason. That means you can help make sure they get the care they need to stay healthy.

Specifically, it's important to emphasize why congenital cardiac care is important — and make referrals for patients who need them. When you do, your impact can last long beyond their visit to the emergency room!

Use these talking points to help start the conversation.

1 Find out if patients have heart defects



“Have you ever had any heart problems — even as a child? For example, did you ever have heart surgery or take medicine for your heart? If you did, I want to make sure you get the care you need to stay healthy.”

It's important to ask patients about their history of heart problems. This is especially true for patients with signs or symptoms that could indicate a congenital heart defect — like trouble breathing, blood clots, or a chest scar. If you don't ask, patients may not mention their heart problems. When you learn that a patient has a heart defect, ask if they're seeing a congenital cardiologist.

2 Explain why patients need lifelong care



“Heart defects are a lifelong condition — even after heart surgery — and they sometimes get worse over time. That’s why you need to see a congenital cardiologist regularly.”

People with heart defects may not know they need to continue to see a congenital cardiologist — especially if they’ve been feeling healthy. Explain that congenital cardiologists can catch problems early to help patients stay healthy and avoid another trip to the emergency room.

3 Describe what a congenital cardiologist does



“A congenital cardiologist is a doctor who’s trained to treat heart problems like yours. They know how to tell if a heart problem is getting worse and how to help you stay healthy.”

Some patients with heart defects may not understand why they need to see a specialist, so it’s important to explain what a congenital cardiologist does. Emphasize that congenital cardiologists know more about heart defects than anyone else — including which medicines or procedures patients may need.

4 Tell patients you can make a referral



“I can refer you to a congenital cardiologist to make sure you’re getting the care you need.”

Reassure patients that you can help them find a congenital cardiologist. Make sure you know how to find congenital cardiologists in your area so you can refer patients who aren’t getting the care they need. If you need help finding congenital cardiologists, check out the Adult Congenital Heart Association Clinical Directory at: bit.ly/ACHDdirectory



To learn more, check out:

- aap.org/CHDcare
- cdc.gov/heartdefects
- chphc.org

