
Materials for internal medicine and family physicians who treat adults

Connect Adults with Heart Defects to the Care They Need

Did you know that about 1.4 million adults in the United States are living with a congenital heart defect?¹

Congenital heart defects are lifelong conditions. That means adults who were born with heart defects need to see a congenital cardiologist regularly to help make sure they stay healthy. But many of them aren't getting cardiac care at all.

You can help change this! As a primary care physician, **you play an important role in connecting people with heart defects to the care they need.**

Take these steps to connect adults with congenital heart defects to congenital cardiac care:

1. Ask patients if they have a history of heart problems — you might have patients with heart defects who've never mentioned they have one.
2. Ask patients with heart defects if they're seeing a congenital cardiologist — a specialist who treats people who were born with heart defects. If they're not, explain why lifelong congenital cardiac care is important. Also talk to young patients with heart defects about transitioning from a pediatric cardiologist to an adult congenital cardiologist.
3. Refer patients who aren't getting the care they need to a congenital cardiologist. If you need help finding congenital cardiologists in your area, check out the [ACHD Clinic Directory](#).

To learn more, check out:

- [The AAP congenital heart defects toolkit](#)
- [Congenital heart defects resources from CDC](#)
- [The Congenital Heart Public Health Consortium](#)

With your help, we can make sure people of all ages with congenital heart defects get the care they need to lead long, healthy lives!

¹ [Congenital heart defects in the United States: Estimating the magnitude of the affected population in 2010](#)

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

People with heart defects need lifelong congenital cardiac care. As a primary care physician, you can help make sure they get it.

Specifically, it's important that you emphasize why people with heart defects need to see a congenital cardiologist — and that you refer patients who aren't seeing one. When you do, you'll help patients with heart defects stay healthy and safe.

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.”

Some patients with a heart defect may not mention it — so it's up to you to find out. 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 last for a lifetime. They can also get worse over time — but they may not cause symptoms right away. That's why you need to see a congenital cardiologist regularly.”

When people with heart defects are feeling healthy, they may not realize they need to see a congenital cardiologist. Explain that congenital cardiologists can catch problems early to help make sure patients *stay* healthy.

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 another physician, 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 seeing one. If you need help finding congenital cardiologists, check out the ACHD Clinic Directory at: bit.ly/ACHDdirectory

Talk to young adults about transitioning to adult care

Many children and teens born with heart defects stop seeing their pediatric cardiologist and never transition to adult congenital cardiac care. That's why it's especially important to talk with young adults about seeing a congenital cardiologist in adulthood — and make referrals for patients who need them. You could say:

“As an adult, it’s important that you see a congenital cardiologist regularly even when you’re feeling healthy. They can help make sure you *stay* healthy.”

To learn more, check out:

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

Social Media Graphic 1

Graphic Text

People born with heart defects need lifelong congenital cardiac care. As a primary care physician, you can help.

Social Media Posts

Twitter

- Do your part to connect adults with congenital heart defects to the care they need by making referrals! Find congenital cardiologists in your area: bit.ly/ACHDdirectory @AmerAcadPeds #CHD #ACHD #CHDCare4Life
- Some patients with a congenital heart defect may not mention it unless you ask! @AmerAcadPeds has tips on starting the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

Facebook

- Do you have patients with congenital heart defects? Ask if they're seeing a congenital cardiologist — and refer patients who aren't. Find congenital cardiologists in your area: bit.ly/ACHDdirectory @American Academy of Pediatrics #CHD #ACHD #CHDCare4Life
- Some patients with congenital heart defects may not mention it. What's the best way to find out if they have one? Ask! @American Academy of Pediatrics has tips for starting the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

LinkedIn

- Do you have patients with heart defects? @American Academy of Pediatrics wants you to talk to them about how important it is to see a congenital cardiologist regularly — even when they're feeling healthy. And refer patients who aren't getting the care they need! Find congenital cardiologists in your area: bit.ly/ACHDdirectory #CHD #ACHD #CHDCare4Life
- Some adults with heart defects may never mention they have one — so it's up to you to find out! Ask patients if they have a history of heart problems, and make referrals to a congenital cardiologist. @American Academy of Pediatrics has tips on how to start the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

Social Media Graphic 2

Graphic Text

Congenital heart defects last a lifetime — and congenital cardiac care should, too. Connect patients with heart problems to the care they need.

Social Media Posts

Twitter

- Primary care physicians play a key role in connecting adults with congenital heart defects to congenital cardiac care! Find congenital cardiologists in your area: bit.ly/ACHDdirectory @AmerAcadPeds #CHD #ACHD #CHDCare4Life
- #DYK? Many people with congenital heart defects aren't seeing congenital cardiologists! Talk with patients about lifelong cardiac care. @AmerAcadPeds has tips on starting the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

Facebook

- Calling primary care physicians! You have a key role to play in connecting adults with congenital heart defects to congenital cardiac care. @American Academy of Pediatrics is asking you to find congenital cardiologists in your area so you can make referrals for patients who need them: bit.ly/ACHDdirectory #CHD #ACHD #CHDCare4Life
- Did you know that many people with congenital heart defects aren't seeing congenital cardiologists? Talk to your patients with heart defects about the importance of lifelong care! @American Academy of Pediatrics has tips on starting the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

LinkedIn

- Primary care physicians play a key role in connecting adults with heart defects to congenital cardiac care! Make sure you ask your patients with heart defects if they're seeing a congenital cardiologist — and refer them if they're not. Find congenital cardiologists in your area: bit.ly/ACHDdirectory @American Academy of Pediatrics #CHD #ACHD #CHDCare4Life
- People with heart defects need lifelong congenital cardiac care — but many of them aren't getting it. It's up to you to explain why lifelong cardiac care is important — even when patients are feeling healthy. @American Academy of Pediatrics has tips on starting the conversation: <https://bit.ly/3aXWN27> #CHD #ACHD #CHDCare4Life

Congenital Heart Defects in Adults: Help Your Patients Get the Care They Need

Did you know?

- About **40,000 babies** are born with a heart defect every year in the United States.² Heart defects are the most common type of birth defect.
- Heart defects are lifelong conditions. Researchers estimate that **1.4 million adults** in the United States are living with a heart defect.³
- Many adults with heart defects aren't getting cardiac care at all. But they need to **see a congenital cardiologist regularly** — even when they're feeling fine.

3 Steps to Connect Adults with Heart Defects to Cardiac Care

As a primary care provider, you have an important role to play in connecting adults with heart defects to congenital cardiac care. Take these steps to help your patients with heart defects get the care they need:

4. Ask patients if they have a history of heart problems. You may learn that some of your patients have a heart defect but haven't mentioned it.
5. Ask patients with heart defects whether they're seeing a congenital cardiologist — and emphasize how important lifelong congenital cardiac care is.
6. Make referrals for patients who need them. To find congenital cardiologists in your area, check out the ACHD Clinic Directory at: bit.ly/ACHDdirectory

To learn more, check out aap.org/CHDcare , cdc.gov/heartdefects, or chphc.org.

² sciencedirect.com/science/article/pii/S0735109701012724?via%3Dihub

³ ahajournals.org/doi/full/10.1161/CIRCULATIONAHA.115.019307