

# Guidelines for the Management of Adults with Congenital Heart Disease

## Highlights for Patients and Families

- If you were told you had a congenital heart defect (CHD) as a child, you should have your heart checked **at least once** at a special adult congenital heart disease (ACHD) center. This center can make sure that your heart is OK and any repairs you had are still working.
- If you were born with a more complex CHD, you should visit an ACHD center at least **every two years**. You should go even if you had surgery for your heart.
- CHD heart problems are very different from “regular” adult heart problems. All staff at your ACHD center should be trained in adult CHD.
- If you do not live near an ACHD center, you will need to travel to visit an ACHD center. Your local heart team should talk to your ACHD center about your care.
- If you have a complex heart defect, all your doctors should check with your ACHD center about any medications or treatments. In most cases all medical procedures should only be done at hospitals that have an ACHD center.
- If you have complex CHD, the following should be done only by your ACHD center:
  - Echocardiograms
  - Pacemaker/ICD implantation
  - Cardiac MRI
  - Catheterizations – diagnostic and interventional
  - Cardiac CT/MUGA
  - Cardiac surgery
- Ask your ACHD center to teach you the name(s) of your CHD and any surgeries you’ve had. Know what you may be at risk for and the signs of new heart problems in the future.
- Your ACHD center should ask you about your emotional and social needs. They should offer non-medical help. This can include mental health support and social services like insurance and employment resources.
- Get an exercise prescription from your ACHD cardiologist. Your exercise prescription should be updated regularly. It is important to live a heart-healthy lifestyle because you can still get other forms of heart disease. Exercising every day can help strengthen your heart and maintain a healthy weight.
- If you need emergency care, make sure your ACHD center knows about it. Even if the emergency is not related to your heart, all emergency care providers need to talk with your ACHD center. Your center can decide if it is safe for you to continue your care locally.
- All women with complex CHD should check with their ACHD center **before** becoming pregnant. With the right care, most women with complex CHD can have a baby. An ACHD center should review the risks of pregnancy to both mother and baby. In some cases more heart treatment should occur before pregnancy begins.
- Certain forms of birth control can be risky for women with complex CHD. You should talk to your ACHD center to find a choice that is safe and effective for you.

The American College of Cardiology and the American Heart Association made rules (guidelines) for taking care of adult patients with congenital heart defects (CHD).

The rules give doctors the most important information for adult congenital heart disease (ACHD). They also say it is important to have special heart centers for adults with CHD. This summary will tell you steps to take and questions you should ask to help take care of your heart. You can find the guidelines online at <http://bit.ly/W8QLdu>.

**Adult  
Congenital  
Heart   
Association**