

GUIDED QUESTIONS TOOL

ACHD EDITION

QUESTIONS TO ASK YOUR CARDIAC TEAM

Congenital Heart Disease (CHD) is a lifelong condition which requires lifelong care in an Adult Congenital Heart Disease (ACHD) Program. Only about 10% of Adults with CHD are seen in ACHD centers, while 60% of patients fall out of care by age 18 due to misconceptions about their long term care needs.

It is vital that adult patients have accurate information about their centers and their condition to aid them in choosing an ACHD Program and making decisions about their care. For this reason, the following questions were designed to help when you talk with your care team. You may not be able to ask all of your questions in one visit. Each patient's condition is different, and not all visits with your team serve the same function. Be sure to read through the list and note which questions are relevant to your current situation. Your situation may change in the future, prompting the need for additional information. This resource document should help with ongoing communication with your care team.

[The ACC/AHA Guideline for Management of Adults with Congenital Heart Disease](#) recommends certain care standards that a quality treatment center should meet; however, not all centers are the same. Some patients and their families may want to contact another center to better understand treatment options. Often, second opinions are reassuring, further building trust between you and your care team.

For more information about congenital heart disease and links to additional resources, please visit our website at conqueringchd.org.



INFORMATION ABOUT YOUR CARDIAC CENTER

When meeting your care team

1. Do you have a dedicated Adult Congenital Cardiology program? Which of your physicians are ACHD board certified? Are your surgeons trained in congenital heart surgery? Are your Electrophysiologists, interventionalists, and nurses trained in CHD? Does this center offer ACHD heart failure and transplant programs? Is this center equipped to perform catheterizations, Cardiac MRI, and CT, on Adults with CHD?
2. Is there an ACHD Program Coordinator on staff? If so, please describe her/his role.
3. Do you have social workers or financial counsellors on staff that can guide patients in applying for medical leave, disability, or financial assistance?
4. How many adult congenital patients do you serve in this clinic/program? How many with my condition?
5. What is the survival rate at this hospital for patients with my condition and procedures I may need? At the time of hospital discharge? After one year? How do your results compare to accepted standards?
6. Do you share your results with national data programs such as the Society of Thoracic Surgeons (STS) Database or Impact Registry to help improve care? Is this information available to the public?

When getting to know your care team

7. If I have questions, need prescriptions refilled, or need to contact my provider for any other reason, what is the best way to reach her/him? Should I contact the physician, the nurse, or the program coordinator? Will there always be someone from the ACHD program staff available?
8. What are the most typical complications associated with my condition? What warning signs indicate that I need to be seen by my doctor or should go to the emergency room?
9. Some adult patients may need or like additional support from parents, spouse, or other family. How can my family members be included in the decision making process? How will the care team give me or my designated proxy information, or reports, before, during, and after any procedure?
10. What support is available for me and my family? Can I talk to other patients that also have congenital heart defects? Is there a local network for people like me? Do you provide nutritional and mental health support?

INFORMATION ABOUT YOUR PROCEDURE AND HOSPITAL STAY

When discussing possible treatment options

11. How many procedures do you, the surgeon, perform on adult patients each year? How many times have you and your program performed this procedure or similar procedures in the last year? Over the last 5 years? Where can I find your outcome data? What are the most likely complications or things that can go wrong with this procedure and how often do they happen?

12. How long with this procedure take? Will I be under general anesthesia or in “twilight” or conscious sedation? How long until I am alert after the procedure? Are there possible alternatives to this procedure?

13. Will I be staying in the pediatric or adult wing of the hospital? Is it a dedicated cardiac unit? Are my children, parents, and significant other allowed on the floor to visit before or after the procedure? Is there someone on staff who is able to explain to a child what is happening to their parent?

14. Will the other specialists and primary doctor whose care I am under be notified of, or consulted with, regarding my hospital stay or any procedures I undergo? Will you coordinate any care I require from other specialties during my stay?

When preparing for a procedure

15. When should I arrive at the hospital? Where do I check in? How many days do you think I will stay in the hospital, including before and after the procedure?

16. Should I bring my current medication with me for my hospital stay? Should I discontinue my prescriptions until I return home or permanently?

17. Will I have any physical restrictions after the procedure? For how long? When can I return my usual activities: work/school, driving, household chores, climbing stairs, sleeping on side or stomach? Do you think it would be beneficial for me to enroll in cardiac rehabilitation after my procedure?

18. What are the signs of possible complications I should look out for after going home? How long should I expect to experience pain? What can I do to relieve that pain? When should I contact my doctor about pain or other symptoms?

19. How long after a procedure is it safe for me to travel/fly? Do I need a note from my doctor for oxygen or my medication?

LOOKING AHEAD

When maintaining your health

20. What are the expected long-term results for this heart defect and its procedure? Will I need another repair? Is there an average life expectancy for someone with my CHD? Are there other possible life-long problems that I need to watch out for?

21. How often should I follow up with an Adult Congenital Cardiologist? What other Cardiac Specialists do you recommend - Electrophysiologist, Behavioral Specialist, or High Risk OB/GYN?

22. Should I take antibiotics prior to dental work?

23. Is it important that I stay as active as possible? What kind of physical activity can I participate in and how much do you recommend for me? Do I have any restrictions on my activity or at work? If so, what are they? Do I have any restrictions on my sexual activity?

24. Should I avoid certain over-the-counter medications or any specific ingredients? Are there certain medications you recommend for cold/flu, trouble sleeping, allergies, or headaches?

25. Are there certain lifestyle behaviors I should avoid? How much should I limit alcohol consumption or marijuana use? Can I get a tattoo or piercing, and, if so, should I pre-medicate for these?



When preparing for the future

26. Is it possible and safe for me to get pregnant? What steps should I take to prepare for pregnancy? Will I be able to care for my children as they grow? Is there a risk of me passing on my heart problems to my future children? What birth control is safe for me to use?

27. Should I have genetic testing done? What are the benefits and/or risks? Will my insurance cover the cost of genetic testing? Should my partner also undergo genetic testing?

28. How will my other medical condition(s) affect my CHD?

29. Will I be able to work as I age? Does my CHD affect what kind of work I will be able to do?

30. Is it safe for me to travel/fly? Fly abroad? What do I do in the event of an emergency away from home? Do I need a note from my doctor for oxygen or my medication?

DIAGNOSED AS A TEEN OR ADULT

After diagnosis

31. Why did my symptoms show up in adulthood and not at a younger age? Why weren't doctors able to diagnose my condition sooner?

32. Am I at greater risk for complications or restricted from certain treatments due to my late diagnosis?

33. Are my siblings, children, or other family members at risk? Should they be screened?

KEY IDEAS

Procedures – Procedures can mean many different things including surgery, testing, or cardiac catheterization. Cardiac catheterization, is not surgery, but can be used to diagnose health concerns or as an intervention for certain conditions. During the catheterization the doctor uses a long, thin, flexible tube that is inserted through a blood vessel.

Number of Procedures – Total number of procedures performed by an individual surgeon may be an indicator of experience, however, some heart defects are rare and the number of times a procedure is performed may be small, even by very experienced surgeons. It's important to consider too, that a very large quantity of procedures performed at centers may limit individualized attention for patients.

Survival Rate – Most babies with Congenital Heart Disease live through their first 30 days after a procedure, which is a common measurement of success for surgeons. It is important to ask about survival rates after 30 days for adults, too. Data for adult patients is still limited, but your care team should be able to provide the data from their own program.

Training – Some doctors have specialty training including board certification in Adult Congenital Heart Disease. Make sure your cardiologist has this training. Some doctors have specialty training including certificates for congenital heart surgery. Inquire if your surgeon has this training or certification.

Data Sharing – Most centers collect information, or data, such as number of procedures, survival rates, and outcomes, using national data programs such as the Society of Thoracic Surgeons (STS) Database or the Impact Registry. Many centers now make this information available to the public. If a center does not give their data to a national data program, or does not share their outcome data publicly, you should ask why.

THE IMPORTANCE OF TRANSPARENCY

At the Conquering CHD our mission is to “Conquer Congenital Heart Disease.” We believe that patient and family empowerment is essential to achieving this mission. We support informed decision-making that will allow patients and families to get the best care possible. Health information that is patient-centered (about the patient), accurate (correct), accessible (available to every person), and communicated in the right way is all part of patient and family empowerment, resulting in improved outcomes in both patient health and family experience.