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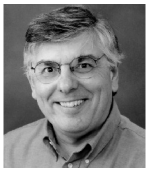
HEART MATTERS A PUBLICATION OF THE ADULT CONGENITAL HEART ASSOCIATION

Congenital Heart Disease and the Long Winding Road to Adulthood



John Reiss, PhD

In today's world, growing up and taking on the roles and responsibilities of adulthood can be a long and difficult process. For the ever increasing number of young people who have a congenital heart defect, this stage of life can be especially challenging. The purpose of this article is to discuss some of the twists and turns that young people with CHD may have to negotiate as they hit their 20s and to suggest some strategies that may make the journey a little easier.

The tasks and challenges for those in their 20s include completing their education and starting a job/career, establishing economic independence, seeing adults as equals and peers, moving away from home, and establishing new social relationships. For many, the 20s is also the time for reexamining personal goals such as: committing to a long-term relationship; if and when to start a family; and asking themselves "What does it mean for me to be an adult?" and "What is my place in society?"

But as a young adult with a congenital heart defect, you must take on these life issues while facing uncertainties inherent in your health condition. Since yours is one of the first generations of CHDers to reach adulthood, doctors have limited information about how your condition may impact your stamina and general well being, if and when you might need to undergo another heart "repair" procedure, and how your condition might change as you reach middle age.

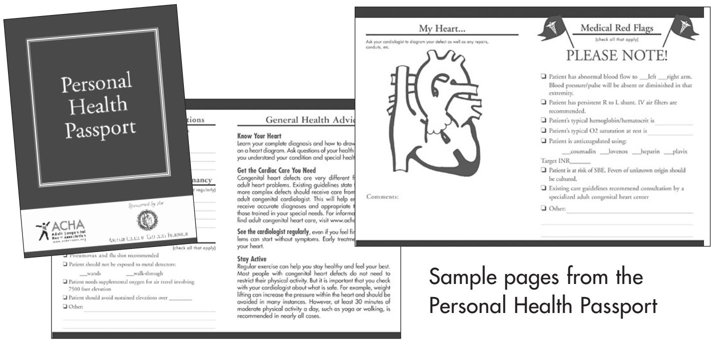
In addition, as a young adult, you are now expected to assume a greater level of responsibility for your own health care, including fully understanding your diagnosis, making decisions about treatment options, following through on your plan of care, and dealing with insurance. As if that were not enough, you may be at the age when your pediatric cardiologist is telling you that it is time for you to find an adult cardiologist and an adult primary care provider. In addition to establishing a positive working relationship with new health care providers, you may be faced with trying to change the ways in which your parents are involved in your health care.

Where to Begin?

An excellent way to start taking charge is to complete ACHA's Personal Health Passport. See how much of the information you are able to complete on your own. You may then want to ask your parents to help you fill in the blanks. If you already have a Personal Health Passport that was completed for you by your parents, this would be a good time to fill out a new one, so that the information it contains is stated in your own words.

Taking the initiative to update your Personal Health Passport may also be a way of beginning to talk about how involved you would like your parents to be in managing your care. Letting go and letting grow is hard for all parents, but it can be especially challenging for parents of young adults with chronic health conditions, and established family patterns and habits can be difficult to break, especially when strong feelings are involved.

To help young adults and their families take a new look at health care roles and responsibilities, researchers at the University of Florida developed a Health Care Transition Workbook. Since becoming more independent in your health care is just one part of becoming an adult, the first section of the workbook focuses on your plans for education, work, and independent living. The workbook then asks you to rate your level of independence on a broad range of health care tasks and activities, including your basic knowledge about your condition; self-care; medications, medical tests, and procedures; the health care visit; transfer to adult care; and transition to adulthood (education, work, and independent living). It also asks parents to look at how they are supporting (or possibly interfering with) your efforts to be more independent. In the last part of the workbook you will identify four or five areas in which you would like to become more independent over the next year and list steps that you and your family will take to meet your goals.



Personal
Health
Passport

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(check all that apply)

❑ Pneumovax and flu shot recommended
❑ Patient should not be exposed to metal detectors:
___wands ___walk-through
❑ Patient needs supplemental oxygen for air travel involving 7500 foot elevation
❑ Patient should avoid sustained elevations over ________
❑ Other: ________

General Health Advi

Know Your Heart
Learn your complete diagnosis and how to draw on a heart diagram. Ask questions of your health you understand your condition and special healt

Get the Cardiac Care You Need
Congenital heart defects are very different f adult heart problems. Existing guidelines state more complex defects should receive care from adult congenital cardiologist. This will help e receive accurate diagnoses and appropriate those trained in your special needs. For informa find adult congenital heart care, visit www.acha

See the cardiologist regularly, even if you feel fi lems can start without symptoms. Early treatme your heart.

Stay Active
Regular exercise can help you stay healthy and feel your best. Most people with congenital heart defects do not need to restrict their physical activity. But it is important that you check with your cardiologist about what is safe. For example, weight lifting can increase the pressure within the heart and should be avoided in many instances. However, at least 30 minutes of moderate physical activity a day, such as yoga or walking, is recommended in nearly all cases.

My Heart...

Ask your cardiologist to diagram your defect as well as any repairs, conduits, etc.

Comments:

Medical Red Flags
(check all that apply)

PLEASE NOTE!

❑ Patient has abnormal blood flow to ___left ___right arm. Blood pressure/pulse will be absent or diminished in that extremity.
❑ Patient has persistent R to L shunt. IV air filters are recommended.
❑ Patient's typical hemoglobin/hematocrit is ________
❑ Patient's typical O2 saturation at rest is ________
❑ Patient is anticoagulated using:
___coumadin ___lovenox ___heparin ___plavix
Target INR______
❑ Patient is at risk of SBE. Fevers of unknown origin should be cultured.
❑ Existing care guidelines recommend consultation by a specialized adult congenital heart center
❑ Other: ________

Sample pages from the Personal Health Passport

This workbook can be downloaded at no charge from the Health Care Transitions website at http://hctransitions.ichp.ufl.edu/resources.html. Otherpossible goals include scheduling your next medical appointment yourself, filling out all of the paperwork when you get to your appointment, and seeing the doctor by yourself. Make a point of carrying the Personal Health Passport with you to your next health care visit, and asking your cardiologist to diagram your defect and any repairs. Write down your questions ahead of time, so you can refer to them during the visit, and keep asking questions until you feel that you completely understand your condition and special care needs. In the past you may have relied on someone else to take notes and remember the details. If you are seeing the doctor by yourself, to help you recall what was said, consider taking notes or using tape recorder, so that you will have a permanent record of what was said. You might then want to share the recording with your parents, your spouse, or others who helped you manage your care in the past.

If you are still attending a pediatric cardiology program, take the initiative to ask if the clinic has an upper age limit. Even if the outpatient program is willing and able to provide care to individuals in their 20s; many children's hospitals have strict in-patient age policies. You cannot assume that you can go to your children's hospital to have surgery if you are 21 years old or older.

The 32nd Bethesda Conference Guidelines state that many adult CHD patients should be seen regularly at a highly-specialized ACHD center. More information on ACHD care guidelines and a listing of self-identified ACHD clinics can be found by clicking on the ACHD Clinic Directory link at www.achaheart.org.

In addition, while a pediatric cardiologist may be willing and able to address your cardiac care needs, you need to have an adult-trained physician who is able to address your primary and preventive health care needs.

Following are some things that you can do to identify an adult primary health care provider:

☐ Ask your current doctors for recommendations;
☐ Consider the doctor that other family members see;
☐ Ask for recommendations from other adults with CHD;
☐ Contact the local Medical Society, American Academy of Family Practitioners, or Internal Medicine Society for referrals. You can find their contact information in the Yellow Pages or at their national websites.

The next challenge is to choose which adult-oriented primary care provider to use. You need information about the doctor and the office in order to make a good choice. Following are some questions that you might ask the office staff when you start to gather information about possible future providers:

☐ What is the doctor's education and training?
☐ What insurance does the practice take? What is the method for payment?
☐ What are the standard fees? Are fees or payment methods negotiable?
☐ How many of the doctor's patients are young adults?
☐ Where does the doctor have hospital admitting privileges?
☐ How long does it take to get an appointment if I have a problem or concern?

You should also make a list of questions to ask the doctor. Following are examples:

☐ May I bring a family member with me to office visits (spouse, parent, sibling, friend)?
☐ How many patients do you see who have a congenital heart defect?
☐ How many patients do you see who are young adults?
☐ How do you involve your patients in health care decisions?
☐ What is the best way for me to prepare for an office visit with you? Should I bring my questions in writing?
☐ Do you use e-mail to answer questions from your patients?

If the doctor is part of a large practice, you might also want to know how likely it is that you will receive care from your personal doctor, and how often you might have to see another member of the practice.

It is a good idea to schedule a visit with the new doctor just to talk and to get important questions answered. You may or may not want to have parents or another person go with you on this visit. Again, one way of helping to remember what was said during the visit, is to take a tape recorder with you, and ask the doctor if you can make an audio tape recording.

Insurance will probably not cover this type of visit, so there will be a cost for this visit, but it is probably a good investment.

Following the visit, ask yourself:

☐ Did I feel comfortable with this doctor?
☐ Do I have confidence in this doctor's ability to address my medical needs?
☐ Did I understand what the doctor said in response to my question?
☐ Am I satisfied with the answers the doctor gave to my questions?
☐ From what I learned from the office staff, will I be satisfied with the care I get from this practice?

If you are not sure that you will be satisfied with the care that you will receive from this doctor, schedule an appointment with the next doctor on your list.

Growing into adulthood and taking more responsibility for your own health care may not be not easy. By identifying the challenges ahead of time and having a plan, your journey through life will be a little easier and much more enjoyable. ■

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