Introduction: Adults with Congenital Heart Disease

Over the past few decades, there’s been a revolution in treating congenital heart defects. Advances in diagnosis and surgery have made it possible to fix or repair most defects, even those once thought to be hopeless. Many people with these defects are now reaching adulthood and living full, active lives. In 2008, more than 1 million people with congenital heart disease have survived to adulthood.

Some defects are classified as cyanotic. This means they cause a blue discoloration of the skin that happens when oxygen levels in the blood are low. If the oxygen levels are normal, the defects are referred to as acyanotic. These terms are often used in the sections that follow.

This online publication describes many defects and the procedures used to repair them. Ongoing care needs and medical problems that can arise are covered, too. You’ll also learn about your specific problem or about employment, insurance, physical activity and childbearing.

It’s important to know that no two people are the same. Your doctor can advise you about your specific heart defect. Reading this information will help you understand what your doctor says and know what questions to ask.

Many people don’t know the name of their heart defect or the types of surgeries they had. If this is true for you, don’t worry — you’re not alone, and it’s never too late to learn about your heart.

Doing some detective work can help your doctor care for you. Ask your parents and your relatives what they were told about your medical condition. Also request all available records from your pediatric cardiologist or the hospital where you were treated. If you can’t get this information, it’s still important for you to see a cardiologist! A doctor with expertise in congenital heart disease will figure out what you have — it may just take longer.

Some patients reach adolescence or adulthood before a defect is noticed. This happens because today diagnostic methods are so sophisticated that defects not previously seen may now be discovered.

Congenital heart defects in adults aren’t common. You’ll get the best care at a center where medical professionals are skilled in caring for people with problems similar to yours. These medical people include board-certified pediatric and adult cardiologists, cardiothoracic surgeons.

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and intensive-care experts, as well as a skilled support team. Often these centers have doctors skilled in special radiology procedures for people with congenital heart disease. As more and more people need this specialized care, centers for adults with congenital heart disease are being formed. You may want to find one. Guidelines for managing adults with congenital heart disease have recently been published by the American College of Cardiology and the American Heart Association.

This information is designed so that you can customize it to your own needs. It’s organized so that you can print out the sections that relate to your defect and concerns. For example, if you’re a young woman diagnosed with tetralogy of Fallot and have questions about pregnancy, print out the sections on tetralogy of Fallot and the one on pregnancy. A man with a history of coarctation of the aorta may want to print out the sections on coarctation and exercise.