

# ACC/AHA guidelines break new ground in adult congenital heart disease

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These days most children born with congenital heart disease live well into adulthood, thanks to innovative surgical, interventional and medical treatments. That means that not only are cardiologists caring for a growing number of adults with repaired heart defects, but the resulting cardiac anatomy and physiology are often much more complex than in the past.

To assist cardiologists in making everyday clinical decisions for this challenging group of patients—and in knowing when to refer patients to specialists with expertise in congenital heart disease—the American College of Cardiology and the American Heart Association have jointly released a comprehensive set of practice guidelines on the management of adults with congenital heart disease (CHD).

The guidelines—the first of their kind in the United States—appear in the December 2, 2008, issue of the *Journal of the American College of Cardiology (JACC)* and the December 2, 2008, issue of *Circulation*. They will be published online on November 7, 2008.

"Adult cardiologists have never before been presented with patients who have such complex congenital heart disease, because in the past, most of these patients did not survive to adulthood," said Roberta G. Williams, M.D., co-chair of the guidelines writing committee. "These guidelines are an important component of a multi-pronged strategy to provide appropriate care for adults with congenital heart disease." Dr. Williams is chair of pediatrics at the Keck School of Medicine of the University of Southern California and vice president for pediatric and academic affairs for Childrens Hospital Los Angeles.

Congenital heart defects can be relatively simple—a small, repairable hole between the left and right sides of the heart, for example. But many forms of CHD are much more complex. A baby may be born

with only one ventricle (the lower chambers of the heart; normally there are two). Or the two large arteries that carry blood away from the baby's heart may be switched, so that blood does not flow through the lungs and pick up oxygen before being pumped to the rest of the body. Heart valves may be misshapen or narrowed. There are many other types of congenital heart defects, and many variations of each, making congenital heart disease one of the most challenging areas of cardiology.

Over the years, cardiac surgeons and interventional cardiologists have become highly skilled at repairing heart defects. That doesn't mean that all children who have undergone surgical procedures are completely cured, however. "That's a common misconception," said Carole A. Warnes, M.D., co-chair of the guidelines writing committee, a professor of medicine at the Mayo Clinic in Rochester, MN, and director of Mayo's adult congenital heart disease clinic. "Some patients leave their pediatric cardiologist and think they don't need to see a physician anymore, and others are seen by a cardiologist with no training in congenital heart disease. We really need to focus on how to better care for this population."

In reality, nearly all patients need follow-up throughout adult life. Some will eventually need additional surgery to correct complications that arise over time. Most will need guidance on how their heart condition affects the important milestones of adulthood, such as employment, pregnancy and physical activity.

Without ongoing care and follow-up by a physician with training in congenital heart disease, the results can be tragic. Worsening of a leaky heart valve may be overlooked until the patient is in heart failure, making surgery highly risky or even impossible. A young woman may be told she cannot have children, when in fact, pregnancy might be possible if managed at a center with expertise in congenital heart disease. A seemingly

routine appendectomy may turn into a life-threatening crisis.

To help avoid such problems, the guidelines provide comprehensive information on the clinical features, diagnosis, and medical, surgical and interventional therapy of a range of congenital heart defects. They also point out common problems and pitfalls, highlight key issues to look for during follow-up, and make recommendations on genetic testing, pregnancy, contraception and physical activity.

In addition, the guidelines call for:

- Coordination of the ongoing care of patients through regional centers of excellence with expertise in adult congenital heart disease;
- Individual and family counseling, including the early education of children on their heart condition and what to do to stay healthy;
- A formal transition process to help teenagers and young adults cross the bridge from their pediatric cardiologist to an adult cardiologist;
- Outreach and education programs to bring patients back into the healthcare system if they are no longer receiving appropriate care and follow-up;
- Education about the risks of infection of the inner lining of the heart or the heart valves posed by dental procedures, tattoos, body piercings, and other procedures that may introduce bacteria into the bloodstream;
- Thorough clinical evaluation of patients before noncardiac surgery or any procedure requiring anesthesia or sedation, coordinated through a regional center of excellence;
- Counseling about safe contraception;
- Consultation before pregnancy, including genetic counseling, so that patients understand the risks to both mother and baby.

The guidelines were developed in collaboration with the American Society of Echocardiography, Canadian Cardiovascular Society, Heart Rhythm Society, International Society for Adult Congenital Cardiac Disease, Society for Cardiovascular Angiography and Interventions, and Society of Thoracic Surgeons.

"We benefited from the diverse experience of adult cardiologists, pediatric cardiologists, cardiac

surgeons, advanced practice nurses, and multiple institutions across the country," Dr. Williams said. "It represents a wonderful collaboration."

Source: American College of Cardiology

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