Top Ten Things To Know

Best Practices in Managing Transition to Adulthood for Adolescents With Congenital Heart Disease

1. Due to scientific and clinical advances, including those supported by the AHA, 85%-90% of children with congenital heart disease now survive into adulthood.

2. Structured programs to facilitate the transition of children with congenital heart disease into adulthood are needed. In 2004, only 48% of these adolescents underwent successful transition.

3. This statement was written to provide guidelines for clinicians [pediatric and adult cardiologists] to promote early and high-quality care and support for their patients with congenital heart disease for successful transitions of care.

4. A transition program should provide health care that is uninterrupted. The ultimate goal of a transition program is to optimize the quality of life, life expectancy and future productivity of young patients.

5. The transition process includes three key elements: pre-transition, transition, and transfer.

6. To prepare the patient for transfer to adult care, discussion of the concept of the care continuum and care transitions should begin in childhood. Beginning the transition process with the adolescent’s participation at age 12 is recommended, although this should be individualized.

7. A primary care provider should be the “medical home” for the patient, coordinating care with other experts and providing family-centered care.

8. The pediatric cardiologist should provide a written adolescent transition plan with a cardiac destination that is shared with the primary care physician and ultimately, an adult congenital cardiologist.

9. Other issues discussed in this statement include non-cardiac medical problems and surgical needs, psychosocial issues, anesthetic issues, medications and drug interactions, anticoagulation, antibiotic prophylaxis and dental care, exercise and sports participation, contraception and pregnancy, new symptoms or acute illness, travel, education, employment, insurance, diet, and genetic counseling.

10. Timing, coordination, and continuity of care are important. A patient-centered smooth transition process requires involvement of:

   • patient,
   • family,
   • pediatric and adult cardiologist,
   • primary care providers,
   • and others who will participate in their care.

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