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Joint policy recommends age-based care of patients with congenital heart disease

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A new policy statement from the Academy and the American College of Cardiology (ACC) aims to influence the care of and improve outcomes for children with congenital heart disease (CHD) by harnessing the efforts of the primary care provider (PCP) and the pediatric cardiologist.

The policy, *The Care of Children With Congenital Heart Disease in Their Primary Medical Home* from the AAP Section on Cardiology and Cardiac Surgery and the ACC, is available at <https://doi.org/10.1542/peds.2017-2607> and will be published in the November issue of *Pediatrics*.

The policy takes a chronological approach, highlighting anticipated problems and emphasizing the PCP's role in the management of patients and their families in various life stages, from the prenatal period to adolescence. Frequent communication, via electronic health records (EHRs) or other means, among all care providers is essential. Care and support provided by the PCP, as outlined in the recommendations, are invaluable for improved outcomes throughout the lifespan.

Complex needs

Many patients are surviving after birth due to advances in the repair and palliation of complex CHD. Pediatricians strive to deliver the best care for these patients in the medical home, but it may be difficult to keep up with their unique health care needs that often require more effort for effective coordination.

Many concerns in children with CHD have come to light over the past several years, including previously unrecognized familial psychosocial stressors, outcome disparities, extra-cardiac system involvement, therapy complications, nutritional challenges, special immunization needs, infection prevention strategies, neurodevelopmental delay and learning disabilities. Although the care of these complex children cannot be simplified, the policy serves as a repository of information that PCPs can refer to in daily practice.

Recommendations

- Promote care coordination and communication among the family and all care providers, especially during times of transition.
- Advocate for caregiver support.
- Facilitate patient access to subspecialty care and medications.
- Be updated on pediatric basic and advanced life support and encourage caregiver cardiopulmonary resuscitation training.
- Augment a neonatal history and physical exam with pulse oximetry screening.
- Encourage growth and development by ensuring adequate nutrition.
- Be aware of infection prevention strategies, including special immunization needs and endocarditis prophylaxis regimens.
- Anticipate extra-cardiac organ involvement, complications of therapy and susceptibility to common childhood illnesses.
- Promote good nutrition and appropriate physical activity.
- Counsel against illicit drug, alcohol and tobacco use, unprotected sex and teen pregnancy.



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- Facilitate transitioning to adult health care when appropriate.
- Support EHR accuracy and access to medical information for all providers.

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Resource

- [The policy statement offers links to 14 advocacy and parental support groups related to congenital heart disease along with other resources.](#)