



What You Can Expect



Young adults with a congenital heart defect will eventually need to transition to adult cardiac care. The transition program at Children's Heart Clinic will help guide you and your family member through this process as he or she works to gain the knowledge and skills necessary to become more independent.

Your involvement is important in this process. Your family member will rely on your support and encouragement as he or she assumes greater responsibility. The goal of the transition program is to help create a bridge between the pediatric and adult cardiology clinics that will allow your family member's transition to be a smooth one.

Moving on from the cardiologists you have always known can bring a mix of emotions, including fear and sadness. The health care team acknowledges those feelings and hopes the benefits of the transition program will make this change less stressful. Guidance through this process will help prepare you and your family member for this change.

Being prepared will alleviate your and your family member's stress and allow the best chance for a successful transition. Topics include:

- understanding your role in the transition process

transition guide for caregivers

Transition is an important process as your family member grows into adulthood and starts making his or her own health decisions.

Your family member will play an active role in setting goals and mastering the skills necessary to ensure he or she is ready for transitioning to the adult care model. Your role as a caregiver is to encourage and support your family member as he or she practices being independent.



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- adjusting to your family member’s growing independence
- knowing where to find support and resources
- making sure your son or daughter has a primary care doctor for non-heart issues.
- understanding the differences between the pediatric and adult care models (including change in processes and expectations)
- understanding changes in confidentiality and consent as your family member becomes a legal adult
- gaining confidence in your family member’s ability to transition to the adult care model.

The Transition Process

The transition process will occur in different stages during adolescence. The program will be introduced around ages 12 to 13. It may seem like an early age to start, but it is important for you and your family member to start thinking about how he or she can begin working toward becoming more independent as he or she gets closer to becoming an adult.

The next step is to develop and implement a transition plan. The plan will be created with your and your family member’s feedback. This stage begins around ages 14 to 15. During this stage, your family member will establish an understanding of the heart condition and how to manage it. He or she will have the chance to practice skills that are necessary to become more independent and self-sufficient.

Once the transition plan is created, it will be reviewed and updated at routine office visits. Transition readiness will continue to be assessed at each visit to help reinforce what he or she already knows and identify any gaps in knowledge or skills your family member will need to succeed independently in the adult care model.

Once your family member is ready for the transition, around ages 18 to 21, he or she will be transferred to the Midwest Adult Congenital Cardiac (MACC) Center where a team of specialists trained in treating adults with congenital heart disease will work with your family member.



Program Goals

- Provide transition support and guidance for you and your family member.
- Provide appropriate education for your family member’s age and development.
- Help your family member develop skills in communication, decision-making, managing his or her health needs and advocating for himself or herself.
- Empower your family member to become more independent and in control of his or her health care decisions.

