

TRANSITION CLINIC



M I D W E S T
Adult Congenital Cardiac Center



help your family
member become
independent



MINNEAPOLIS
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 The Children's
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Independence



Adolescents and young adults with congenital heart disease need to learn how to become their own best advocate. This means taking an active role in making decisions about their treatment and care.

Until now, you have been your family member's best advocate and have made all their decisions. As your family member's grows older, he or she will start becoming more independent in making decisions and taking responsibility for his or her health. Help support and encourage your family member as he or she learns how to communicate with the health care team.

Tip

Your family member needs to learn to discuss questions and concerns with his or her health care team directly. Practice

now so your he or she gets more comfortable and competent as he or she gets closer to being an adult.



Let Go

Until now, you have been your family member's best advocate and have made all their decisions. Becoming more independent is a natural part of your his or her development. As your family member becomes more independent and involved in decision-making, "letting go" and developing confidence in your family member may be hard.

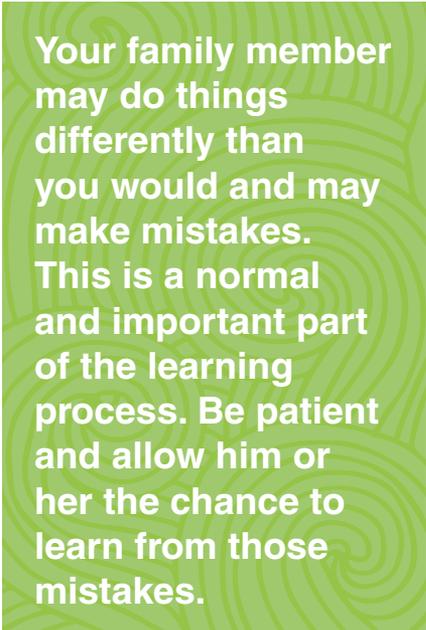
Your support and encouragement will help your family member develop self-esteem, self-worth and life skills, and it will help boost his or her confidence in making health care decisions.

You might wonder if your family member is ready for this. In order for youth to become more independent in managing their health, they need to be allowed opportunities to practice. Some youth may feel comfortable with this transition process while others may have more difficulty.

Some youth choose to continue to include their caregiver(s) in health care decisions. This becomes important at age 18 when a teen becomes a legal adult.

If your family member gives consent once he or she turns 18, the health care team will be able to discuss personal health information with you.

If he or she is unable to make health care decisions on his or her own, you can consider options for guided-decision making. It is important that you try to continue to encourage and foster independence in your family member.



Your family member may do things differently than you would and may make mistakes. This is a normal and important part of the learning process. Be patient and allow him or her the chance to learn from those mistakes.

Help Promote Independence

You are used to being your family member's advocate and making health care decisions for him or her. This includes speaking on his or her behalf at appointments, scheduling appointments, requesting refills and filling prescriptions, as well as providing transportation to and from appointments.

It may take time to adjust during this process, so move at your own pace so that you and your family member can both feel comfortable.

Encourage your family member to:

- respond directly to questions from the health care team
- prepare and ask questions for the health care team
- spend some time alone with the health care team, increasing each visit until he or she feels comfortable attending most or all of the appointment alone. He or she can update you with the key issues at the end.
- give symptoms to the health care team and help him or her fill in details, if needed
- learn all medicines, dosages and what each is used for
- request refills and filling prescriptions at the pharmacy
- make follow-up appointments, in person or by phone.



Tip
Help your family member understand his or her heart defect and be able to describe or draw pictures of it.

How to Help at Home

Encourage your family member to increase independence at home too! Your family member's abilities may vary, but there are many things you can do to help promote independence at home.

- Give your family member responsibility for chores.
- Allow your family member to go out with friends alone, as long as he or she tells you where they are going, what they will be doing and when they will be home.
- Teach your family member to prepare meals.
- Enroll your family member in driving class.
- Encourage your family member to play in sports or get involved with an after-school activity or community group.

Set a good example. Your family member looks at you as a role model.

Communicate Well

Adolescence is a challenging time for both you and your family member, as he or she learns to navigate the world and learn more about him or herself. This can make communication difficult at times. Disagreements are not uncommon.

You two may need to negotiate and take all opinions into consideration when compromising on a solution. Remember that your family member needs space to grow and make mistakes. Taking time to listen to what he or she has to say may improve your chances of understanding your family member and his or her perspective.

To help you avoid conflict and learn to negotiate, use the following tips.

- Talk with your family member when you both have free time.
- Avoid getting angry or raising your voice during disagreements.
- Take a break if your family member becomes frustrated or starts to argue. Come back together when you both have had time to “cool off.”
- Actively listen when your family member talks.
- Do not interrupt your family member when he or she is speaking.
- Try to compromise on a solution that meets both of your needs if you are in a disagreement.
- Offer another suggestion if you disagree with a solution your family member suggests. Tell him or her why you disagree with the solution.
- Support your family member by letting him or her have the chance to develop skills of independence.
- Always let your family member know that you love and support him or her.

Tip

Respectful disagreements can help your family member learn how to argue in a constructive way. Avoid using generalities like “you always” or “other kids never.” Use “I” statements to make your point. “I get nervous when you wait to make an appointment.”



Take Care of Yourself

Caring for a family member with a chronic heart condition can be exhausting. It is easy to put your needs aside to focus on your family member's, but this can be damaging to your health and well-being. It may even affect your ability to care for and support your child.

The transition process is a major change in both your and your family member's life. It requires planning and support from your transition team. Things you should do for your health and well-being:

- Eat healthful foods and beverages.
- Get regular exercise (at least 5 days a week).
- Get regular sleep (at least 7 hours each night).
- Talk to others when you need to vent or when you need support. Talk with your health care provider if you feel overwhelmed.
- Set aside family time.
- Ask for help when you need it. Accept help from others.
- Take time for yourself.

Tip

Taking care of yourself during the transition process is important for you and your family member. This is especially true as you both adjust to your new roles.



Resources

- American Congenital Heart Association:
achaheart.org
- American Heart Association:
americanheart.org
- Best Practices in Self-Advocacy Skill Building:
parentcenterhub.org/repository/priority-selfadvocacy
- Children’s Heart Foundation:
childrensheartfoundation.org
- Congenital Heart Disease Information Network:
tchin.org
- Cove Point Foundation:
pted.org
- Helping Hearts:
helpinghearts.org
- Kids Health:
kidshealth.org (Click on the “For Parents” tab.)
- Kids with Heart: National Association for Children’s Heart Disorders:
kidswithheart.org
- Little Hearts:
littlehearts.org
- Parent to Parent USA:
p2pusa.org
- The Children’s Heart Foundation:
childrensheartfoundation.org
- Tips and Resources for Parents for Families Who Have a Child with a Congenital Heart Defect:
helpstartshere.org (Search for “congenital heart defect” and choose the “Tips and Resources” link.)

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