



Develop and Practice Skills



learn to advocate for yourself

As you grow older, you will start becoming more independent in making your own decisions and taking responsibility for your health.

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 your treatment and care. These issues may be complicated, so it is important that you know with whom to talk and how to communicate.

During your childhood and adolescence, your caregiver(s) made decisions for you. As you start to become more independent and make decisions about your health, you can rely on your caregiver(s) and your transition team for support with any complex issues.

Your transition support team can also help answer any questions you may have, as well as offer emotional support. However, it's important that you become assertive and learn to discuss your questions and concerns with your health care team directly.

It's good to start practicing now so you become more comfortable advocating for yourself as you get closer to being an adult. This will also help build your caregiver(s)' confidence in you along the way.

Your First Steps

It is important that you understand as much as you can about your heart defect and any potential problems you may have. The following will help you take steps to becoming more independent.

- Spend at least some of the time talking with your health care team without your caregiver(s) in the room.
- Prepare questions before you meet with your health care team.



MINNEAPOLIS
HEART
INSTITUTE

Allina Health
ABBOTT
NORTHWESTERN
HOSPITAL

Children's
MINNESOTA



The Children's
Heart Clinic

- Ask questions and write down important information.
- Learn the name of your heart defect and be able to describe or draw a picture of it.
- Know your medical history, including any surgeries.
- Know and keep a list of your medicines, dosages, and the purpose of each medicine.
- Learn the potential risks you face as an adult.
- Know how to identify signs of worsening heart-related problems.
- Know what exercise restrictions you have, if any.
- If you are sexually active, talk to your adult congenital heart defect (ACHD) team about what forms of birth control are safe and talk to your ACHD team before you become pregnant.
- Carry a medical summary with you and make sure you share this information with all doctors you see, including your primary care doctor, emergency department doctor or dentist.

Important Skills to Develop

You will need to work on certain skills that are necessary to be able to communicate well with your health care team. This will be hard at first, but with practice during the transition process, these skills will become easier and will build your confidence as your work toward transitioning to the adult care model.

- Talk to your health care team about your medical problems.
- Ask questions about your heart defect and understand how it may affect other areas of your life.
- Follow your treatment plans.
- Make appointments on your own. Follow up regularly with your health care team.
- Stay healthy by eating healthful foods, exercising, taking your medicines and avoiding high-risk behaviors (such as smoking, drinking alcohol or using drugs).
- Be aware of your physical and emotional health needs and get help if you have any medical or mental health concerns.
- Develop a plan when you have an emergency and know what hospital to go to.
- Have a health care directive, a health care agent or both to convey your health care wishes if you are unable to.



Resources and Support

- American Congenital Heart Association
achaheart.org/your-heart
- Kids as Self Advocates
fvkasa.org
- Speaking Up
selfadvocacyonline.org/learning/speakingup/
- Kids Health
kidshealth.org
- Youthood
youthood.org
- Youth in Action!
ncwd-youth.info