

Preparing For College When You Have Congenital Heart Disease

A PUBLICATION OF THE ADULT CONGENITAL HEART ASSOCIATION • WWW.ACHAHEART.ORG • 888-921-ACHA (2242)

Going to college is an exciting time filled with new friends and experiences. When you have congenital heart disease (CHD), it can be overwhelming or tempting to put your care on the back burner. It's very important that you stay in care and are as prepared as possible. By following the tips outlined in this resource, you can continue maintaining good health while you further your education.

Things to Do Before College

Know information about your CHD. It is crucial
to know what your diagnosis is and what type of
surgeries you have had. It's also important to be
able to tell others about them. In addition, you need
to know other significant information. This includes
whether you have a mechanical valve, pacemaker
or ICD.

It is also essential to talk to your doctor and ask questions. Have him or her draw what your heart looks like and ask him/her to help you write down other important medical information using ACHA's Personal Health Passport. You can also copy this information into your phone's Medical ID or add the information to a flash drive. Learn how to do so on your Apple or Android mobile device.

If you are still seeing your pediatric cardiologist, ask him or her to refer you to an ACHD specialist. If you are going away for college, it's important to establish care with a local ACHD provider.

2) Learn the names and dosages of your medications. You also need to know why you take them. If you have any medication allergies, it is also important to know the reaction you have if you take them. If you are on medications requiring regular bloodwork, talk to your doctor about where he or she would recommend getting this done. If you take Coumadin (warfarin), you may be eligible for a home monitoring device. That way you can check your INR yourself and report the results to the doctor's office.



- 3) Prepare to transition to adult congenital heart disease (ACHD) care. If you are still seeing your pediatric cardiologist, ask him or her to refer you to an ACHD specialist. If you are going away for college, it's important to establish care with a local ACHD provider. Start this process early. That way you can get an appointment set up and your records sent to the provider's office. If you need help identifying an ACHD program, use ACHA's searchable <u>Clinic Directory</u>.
- 4) Maintain insurance coverage. It's important to talk to your insurance company about which providers and services are covered. This is especially necessary if you are going out of state for school. If your hospital or provider isn't in-network or covered at all, ask about the process for appealing that decision. This can be based on continuity of care. Other options for healthcare coverage include student health insurance available through your college or university, Marketplace healthcare plans and in some instances, Medicaid. Click the links to learn more about how to apply and if you qualify for a subsidy through the Marketplace.

When You Arrive at College

Set up an appointment with student health. This
is important so the healthcare team can become
familiar with you and your medical history. Your
student health center can also be helpful in

identifying additional resources. These can include the following:

- Disability Services: Some schools have student disability services or centers. These can be helpful if you need to talk to your professors about accommodations or a leave of absence due to a medical emergency, procedure or surgery during the school year.
- Mental Health Services: Even if you don't need them right away, it is good to know what resources are available and how to access them if you need them. Many colleges offer free and confidential counseling services to students.

Get plenty of rest, eat a balanced diet, exercise and engage in healthy activities to relieve stress.

- 2) Set reminders. Sometimes it can take a while to get adjusted to a college schedule. Set reminders to take your medications and add your appointments to your calendar. If you have a pacemaker, you should also add reminders for when you need to submit a transmission to your doctor.
- 3) Identify a pharmacy for medication refills. Set reminders for when you need to request a refill. That way you won't run out of medication. You can also look into mail delivery services for your medications through your insurance or local pharmacy for added convenience.
- 4) Prepare for emergencies. Tell your roommate, friends, and resident advisor about your CHD. Give them the contact information of who to call if you have a medical emergency. Let them know about the location of your Personal Health Passport and medical ID on your phone. Wearing a medical alert bracelet or necklace with your most important health information is also a good idea.

During College

Obtain regular dental care. Good oral hygiene
is extremely important for CHD patients. If you
need to take antibiotics before your appointment,
make sure you have a prescription and remember
to pick up it up from the local pharmacy. For more
information on why dental care is so important,
visit www.achaheart.org/dental.

- 2) Take care of yourself. Get plenty of rest, eat a balanced diet, exercise and engage in healthy activities to relieve stress. This can include going for a walk, doing yoga, meditating, painting, etc. Avoid things that can have a negative effect on your heart health, such as illegal substances, energy drinks and excessive amounts of alcohol. College is filled with many social opportunities, but it's important to know your limits. Prioritize what events or clubs you'd like to participate in. If you feel stressed, remove something from your schedule and use mental health or counseling services if needed.
- 3) Listen to your body and be an advocate for your health. If you aren't feeling well or feel that something is wrong, make an appointment with your ACHD specialist to discuss your symptoms and concerns. Don't be afraid to speak up to your friends, professors or healthcare staff.

Helpful Tip: If you have a medical emergency or hospitalization, be sure to ask that your medical records are sent to your primary care doctor and ACHD doctor.

Remember, you are not defined by your CHD, but it is a part of you who are. Being proactive with your care and preparing ahead of time is important to maintain good health so you can achieve your goals.

If you have questions about preparing for college and would find it helpful to talk to someone with a similar experience, the following ACHA resources are available for you:

Heart to Heart Peer Support Program www.achaheart.org/H2H

ACHA's Online Community community.achaheart.org

Additional information can be found at www.achaheart.org

- @ACHA_Heart
- **f** @AdultCongenitalHeartAssociation
- @ACHA_Heart