



Conquering CHD



TRANSITION CHECKLIST

WHEN YOU WERE A CHILD WITH CHD...

you probably had someone who helped you with all sorts of things related to your heart health and its impact on your life.

As you get older, it is important that you learn how to do these things by yourself. This Conquering CHD Transition Checklist can help as you think through all the things that may come up.



THIS CHECKLIST WILL HELP YOU MANAGE YOUR OWN CARE

as you reach adulthood, talk to your doctors and nurses, and transition as you move on from your pediatric doctor to an Adult Congenital Heart Disease doctor. It may be helpful to use a notebook or notes app to keep track of the information you will be expected to know.



Hospital

Doctor's Name

Phone

Email

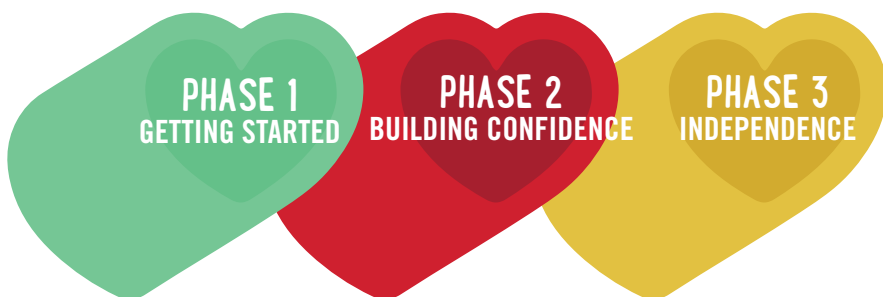


This Checklist comes in phases and can be started at any age. Start at Phase 1, and, once you feel comfortable with it, move on to the next phase. Once you are comfortable with Phase 2, move on to the last one. The phases are organized by complexity. Phase 1 covers basic information and skills, and gets harder

with each following phase. If you need to, you can always go back to any of the phases and go over them with your care team. While help from your parents or trusted advocate is okay too, this checklist is up to you to complete – after all, the goal is for you to be able to take control of your own health care!

HOW TO USE THIS CHECKLIST:

This tool will guide you through the topics related to your CHD and care, beginning with the basics and building to the difficult topics.



PHASE ONE GETTING STARTED!

This is a good place to start when just beginning to learn about the details of your CHD and care. You may already know some of this information, but some of it may be new to you. Use this Phase to double check the things you know and ask questions about the topics you don't. Use a notebook to keep track of your questions and what you learn.



1. KNOW YOUR HEART

What Has Already Happened

Be able to:

Name or describe your heart defect(s) and related conditions.

Tell someone else about any allergies you may have to medications.

What Could Happen

You need to:

Know that there is no cure for CHD. Even if you have had surgery, you need to continue to see your doctor and may need additional treatment in the future.

What Is Going on Today

Be able to:

Talk about any health issues that have been going on for a while or any new changes you may be noticing, such as pain or difficulty with activities/ exercise.

List all the medications or pills you are taking right now. Describe the medications you are taking today, the dosage, and why you take the medication. If you are more comfortable, keeping a list of your medication on your phone, in your pocket, or wallet may make this easier.

Talk about all the things you can do physically at school, work, or during free time and those activities that are not a good idea.

Know that some of the care you may need may come from someone other than your heart doctor. Be sure to write down the name and/or kind of doctor you need to see for other health issues. Ask how best to make sure all of your doctors know your whole story.

2. STAY SAFE

You need to:

Talk with your care team about what heat, sun, and not drinking enough fluids can do to your body.

Talk with your care team about other ways to keep yourself safe and healthy during school, work, and other activities.

Talk to your care team about the amount of sleep you need.

Talk to your care team about premedication before seeing a dentist.

3. SPEAK UP

Ask Questions

Write down any questions you have for your doctors and nurses.

Ask or show your doctor your list of questions.

Ask your doctor to draw a picture of your heart next to a picture of a normal heart, so you can take it home with you.

Use Your Voice

Practice doing the talking at doctor's appointments. It's okay to bring your parents or a friend with you, but you need to be the one to lead the talk with your doctors and nurses.

Speak Up for What You Need

Be honest. Your care team wants you to be the best you can be. They need to know what's going on, what might be wrong or different, what you like and don't like about your care, or even things that scare you.

If you do not understand what your doctor says, ask for more information or an easier explanation. Don't be afraid to say "I don't get it." Everyone gets confused and CHD comes with a lot of complicated information.

4. BE INVOLVED IN YOUR CARE

Make a Plan to Pick Your Adult CHD Team

Talk to your Pediatric Heart Doctor about potential adult CHD programs in your area.

Keep Track of Your Records

Consider wearing a Medical ID and/or put Emergency Contact Information in your phone, in case of emergency.

Plan Your Own Appointments

Know which doctors you need to see and why. Know how often you need to see each one. If you don't know, ask your doctor.

Stay in care with your general doctor as well. Ask your pediatrician about appropriate adult general doctors for you.

Manage Your Own Medication

Know which medications you are taking and why.

Know what could happen if you miss any doses of your medication.



5. MEDICAL INSURANCE

Make Sure You're Covered

Know what insurance you have. Keep your insurance card in a safe place or know where your parent/guardian keeps it.

6. WIN AT SCHOOL AND WORK!

Talk to your doctor if you feel like you're having a difficult time learning. This may mean not being able to get things done on time, finding it hard to concentrate, not being able to finish tests in the time you are given, or other ways thinking may be hard.

Ask your heart doctor if you have any work restrictions.



7. YOU ARE NOT ALONE.

Find Those Who Can Help You

A transition coordinator or mentor can help guide you through care as you go from being a kid to an adult. Ask your care team if your hospital has either of these options.

Social Workers and Mental Health Professionals can be important partners in helping you cope as you get older. Ask your care team, employer, or school if there is one available to you.

Get Connected with Others Like You

Speak to other patients about their experiences, and lean on each other for support. You can find other patients at family events hosted by your hospital, for example. Ask your care team where to get information on upcoming events.

Check out your local Conquering CHD chapter for teen and adult focused events, or ask your care team about other local groups.



YOU'VE MASTERED
PHASE 1

CONGRATULATIONS!

NOTES



PHASE TWO **BUILDING CONFIDENCE!**

This is a good time to practice doing some things on your own, like talking to doctors or making your own appointments. It's also a good time to begin thinking about how your CHD can affect your time with friends, at school, work, or during any activities.



1. KNOW YOUR HEART

What Has Already Happened

Be able to:

Talk about your heart defects, operations, tests, or other medical issues you've had.

What Is Going on Today

Be able to:

Know how to tell if your medications aren't working and what side effects they may cause.

Know whether you need antibiotics before going to the dentist, and which doctor will prescribe them.

What Could Happen

You need to:

Know what health problems you may have in the future and what signs you should keep an eye out for.

Know which activities aren't a good idea for your heart long term, when it comes to school, work, or other activities.

Know what kind of doctor is best for you as you get older.



61% of young adults with a CHD will stop seeing a cardiologist by the time they are 18 years old.



Approximately 42% of adults with CHD presenting at an adult CHD clinic had a gap in care of greater than 3 years.

2. STAY SAFE

You need to:

Talk with your care team about the impact of drugs and alcohol on your body.

Talk with your care team about the risks of tattoos and piercings and how to stay safe. Know whether you should take antibiotics before either.

Begin to discuss reproductive health with your doctor, especially if you are or plan to be sexually active. Know if it is possible and safe for you to get pregnant.

Understand the importance of mental health. Discuss how to manage stress with your care team.

Talk to your care team about safety when traveling.

3. SPEAK UP

Ask Questions

Continue to write down any questions you have to ask your doctors and nurses at your next visit.

Use Your Voice

Talk to an adult about what is happening in your life besides just how your body feels. Talk about school, work, and friends.

Speak Up for What You Need

If something feels off with your body or your emotions, tell someone. Tell a friend, teacher, parent, counsellor, nurse, or doctor.





4. BE INVOLVED IN YOUR CARE

Make a Plan to Pick Your Adult CHD Team

Discuss possible Adult Congenital Heart Disease (ACHD) doctors with your pediatric heart doctor. Write down the name and contact information for the ACHD doctor your pediatric doctor recommends.

Know the closest Adult Congenital Heart Disease (ACHD) Program. This is more than just a heart doctor. The program takes care of all things CHD for adults.

Keep Track of Your Records

Consider using a free health app on your phone to keep your emergency medical information and doctor's contact numbers.

Plan Your Own Appointments

Talk to your doctor about troublesome things to look for, or red flags, that tell you to go to the doctor even before your next appointment.

Know when you should go straight to the Emergency Room.

Manage Your Own Medication

Know how to talk to your doctor and pharmacist about how all of your medications work together.

Know which pharmacy fills your prescriptions.

5. MEDICAL INSURANCE

Make Sure You're Covered

Before going to a new doctor, know how long your current insurance will last and possible options for your future.

Before going to a new doctor, clinic, or hospital, make sure your insurance is accepted.

Know if your insurance will help pay for your ACHD care.

6. WIN AT SCHOOL AND WORK!

Talk to your doctor about who may be able to help make school, work, or even daily activities of life easier for you.

7. YOU ARE NOT ALONE.

Find Those Who Can Help You

Cardiac rehab may help you get better faster, after an operation. Ask your care team about this service prior to any procedure.

Counseling from a Cardiac Behavioral Therapy Team or a counselor specialized in chronic illness may also be a useful tool to heal mentally and emotionally. Ask your care team if this is available to you.

Get Connected with Others Like You

Join the Conquering CHD Teen and Adult Patient Closed Facebook Group. <https://www.facebook.com/groups/CCHDTeensandAdults>

Ask your care team about support or volunteer opportunities in your area.



**YOU'VE MASTERED
PHASE 2**

CONGRATULATIONS!

NOTES



PHASE THREE INDEPENDENCE!

This section covers more challenging tasks that you need to be able to do all by yourself. It will help you take control of your care and prepare you for the final steps of moving your care to an Adult Congenital Heart Disease Program. You can do it!

1. KNOW YOUR HEART

What Has Already Happened

Be able to:

Describe details of previous care, including location of treatment, previous doctors, symptoms, concerns, and other important information related to your heart and overall health.

What Is Going on Today

Be able to:

Talk about any recent medical tests you have had and the results. (Examples may include MRI, X-Ray, lab tests, blood work, stress tests, echoes, and others.)

What Could Happen

You need to:

Know that it is important to keep seeing the heart doctor, even if you feel okay, so you can avoid or catch any problems early.

Know what to do if you need care when traveling without a partner, parent, or guardian.

Know the chances that your children may also have CHD.

So much about long term outcomes for patients like me is uncertain. That's why it's so important to keep seeing my cardiologist, even when I am living my best life!

- Eva, 25, Atrial Septal Defect

2. STAY SAFE

You need to:

Talk with your care team about the risks of sexual activity, and know how to stay safe.

Talk with your care team about the risks of pregnancy and if it is right for your body.

Know which birth control is safe for you to use.

3. SPEAK UP

Ask Questions

Continue to write down any questions you have to ask your new doctors and nurses, as you transition to adult care. Here are some possibilities:

- Where do I go to visit you?
- Will I always see you, or is there someone else I might see?
- Does the program include other CHD specialists?
(For example, electrophysiologists, mental health, high risk OB/Gyn, CHD surgeons)
- Will you talk to my other doctors or do I have to?
- How can I reach you between clinic visits?
- If I need surgery, where will it be done?
- I started feeling something new, what could it be?

*For more suggestions, see our Guided Questions Tool - ACHD Edition

Use Your Voice

Share your story and all the details about your heart when meeting new doctors or members of your care team.

Speak Up for What You Need

If something seems off with your care or you aren't comfortable with a doctor's plan, it's okay to ask to talk to another doctor for a second opinion.

4. BE INVOLVED IN YOUR CARE

Make a Plan to Pick Your Adult CHD Team

Talk to your pediatric heart doctor about being there with you when you meet your new doctor for the first time. This can even happen via Skype or Facetime.

Talk about how and when your pediatric heart doctor will talk to your new ACHD doctor.

Learn more about Adult Congenital Heart Disease clinics by visiting:

www.conqueringchd.org

Keep Track of Your Records

Keep your health records in one place, either on paper or on a computer.

Keep a back-up as well. Keep track of things like the names of your heart defects, any other medical problems, tests, operations, and medications.

List where and when you had the tests or operations and the name of the doctors who helped you.

Make sure your new doctors and/or hospital can get your medical records from where you were treated before.

Plan Your Own Appointments

Schedule your own appointments.

Make sure you know what school, work, or social activities might be affected and how you will get to your appointment. Know if you need to bring anything with you.

Attend regular heart check-ups, even if you feel fine. CHD can change unexpectedly.

Identify what might make it difficult for you to continue going to the doctor. Talk about these challenges with your doctor or care team. (For example, appointment availability, transportation, insurance, or conflict with work or school)

Manage Your Own Medication

Know how to get more medication before your prescription runs out.

Know which pharmacy your insurance lets you use.

5. MEDICAL INSURANCE

Make Sure You're Covered

Know if you need clearance from your insurance company before you see a doctor or have a test or procedure.

Know how to get a referral for a doctor's appointment, test, or procedure, if needed.

Know if your insurance needs to be updated and what options are available.

NOTE: If you are older than 26, you most likely can no longer be covered by your parents' insurance.



6. WIN AT SCHOOL AND WORK!

Talk to your doctor, your teachers, your school counselor, and even a social worker about what you want to do in the future for school or work.

Talk to a social worker about short and long-term disability if you need time off because of your health.

7. YOU ARE NOT ALONE.

Find Those Who Can Help You

A Social Worker can help you understand your medical bills and can help with applying for disability if it is right for you.

A Social Worker or the human resources person at your work can help you understand Family Medical Leave if you get sick. Ask your care team, school, or employer if they have one of these people to help you.

Get Connected with Others Like You

Continue to check in with your “heart friends”. As you get older and experience new things, it can be helpful to talk to others who know what you are going through. If you have not yet found a good group, ask your care team to connect you to local patients or organizations.





**CONGRATULATIONS!
YOU HAVE COMPLETED THE
TRANSITION CHECKLIST!**

NOTES



Find more resources, available through
Conquering CHD, at www.conqueringchd.org or contact
us by email at ACHD@conqueringchd.org.

