

Empower

Understand

Thrive



EMPOWER

MY CONGENITAL HEART



A Guide to *Communicating* With Your Healthcare Team

The First Step Is a Conversation

Successfully navigating a chronic illness like CHD can be difficult. You may feel like you need all the information or that you need to know every answer. But often the first step in any of this is learning to communicate better with your medical providers so you can feel comfortable with your care, make shared decisions with your team, and ensure you and your provider have the information you need.

This guide was developed to help you navigate your journey with more confidence. Know that others are going through this too. You are not alone in your experience.



EMPOWERMENT

You don't need to know every medical detail to speak up. You are the expert on how you feel and what matters to you.

Managing CHD Over Time

Having congenital heart disease is a lifelong journey that requires you to navigate the healthcare system. With that comes testing, possible surgeries or interventions, new diagnoses, and possible mental health challenges. It is normal to have questions, and getting the answers you need can be challenging.

You aren't alone in feeling this way.

- ◆ **73%** of U.S. adults say the healthcare system fails to meet their needs in some way¹.
- ◆ **64%** wish healthcare providers would take more time to understand them; **49%** say they don't always feel heard by healthcare providers¹.
- ◆ **28%** of the U.S. population experienced a barrier accessing a care specialist².

Among people who had trouble seeing a specialist, these were the top five barriers²:

- 1 Difficulty getting an appointment
- 2 Long wait for the next available appointment
- 3 Difficulty with costs/affordability
- 4 Appointments being canceled by the specialist
- 5 Personal/family responsibilities

Getting the care you need can be hard. That is why it helps to know how to communicate with your team (doctors, nurses, medical staff). It can help you feel more confident that you are receiving the right care. You are the most important member of your care team.

In this guide, a “provider” is anyone who gives you medical care, such as a doctor, nurse practitioner, physician assistant, or nurse.

Chandra's Story

Chandra

Tetralogy of Fallot

Navigating life with CHD has been no cakewalk. As a child, I had to experience so many things that were completely out of my control. I had doctors, parents, and other adults making decisions and helping me understand what was happening, but I didn't always have the words or the voice to express how I felt fully. At that age, you don't necessarily understand the medical terminology, the seriousness of certain situations, or even how those experiences may affect you emotionally later in life. You simply learn to go through it.

As I have gotten older, living life with CHD has become something I have had to learn—and something I know I will continue learning during my journey. One of the biggest changes has been going from having other people handle my care to becoming my own primary navigator. Suddenly, the responsibility of understanding my medical history, asking questions, communicating with medical professionals, understanding terminology, and speaking up for myself became mine.

That transition has not always been easy. There are moments when I have felt overwhelmed, confused, or even frustrated because I didn't know what to ask or how to explain what I was experiencing. Sometimes, you can feel like you should already know these things simply because you have lived with CHD for so long. But the reality is that living with a condition and understanding how to manage it are two very different things.

I have also learned that becoming an adult with CHD means realizing that the journey doesn't necessarily end when you grow up. The appointments may change, the conversations may change, and the responsibilities may change, but CHD is still a part of your life. You are constantly learning to balance your health with work, relationships, family, everyday responsibilities, and the emotional burden of knowing your heart has a history others may not see.

There have been times when I wondered if I was the only person who felt this way—like I was supposed to have everything figured out when I was still learning. I have learned that it is fine not to have all the answers. It is okay to ask questions. It is okay to say, "I don't understand, can you explain that to me?" And it is okay to need support while learning how to advocate for yourself.

My experience with CHD has taught me that self-advocacy doesn't happen overnight. Finding your voice takes time, especially when you spent so much of your childhood having other people speak on your behalf. As an adult, finding that voice has been one of the most important parts of my experience.

If there is one thing I hope another person living with CHD takes from my story, it is that they are not alone. If you have ever been overwhelmed by terminology, confused by your medical history, unsure what questions to ask, or frustrated by the responsibility of managing your own care, those feelings are real and understandable. We are all learning as we go.

Living with CHD may be a lifelong experience, but we don't have to manage it alone. Sometimes, simply knowing that someone else has felt the same uncertainty, frustration, or fear can make the journey look a little less lonely.

Patient Burnout / Healthcare System Fatigue

Patients can experience fatigue from having to communicate the same things over and over. This is sometimes called *patient fatigue*, *patient burnout*, or *healthcare system fatigue*.

Your healthcare team wants to give you great care, but there can be systemic and bureaucratic barriers between you and your healthcare providers. Working through these barriers can be tiring, confusing, and frustrating. Getting the care you need is not always straightforward, and sometimes it takes a few extra steps.

Living with and managing a chronic illness (or multiple) can often feel like a full-time job on its own. The amount of administrative and logistical work involved in getting the care you need can be both physically and mentally exhausting.

Ways To Ease Burnout

If you have a trusted friend or family member, it may be helpful to involve them in the tasks that contribute to burnout, such as:

- ◆ scheduling appointments,
- ◆ transportation to/from appointments,
- ◆ picking up prescriptions,
- ◆ sorting out insurance specifics, or
- ◆ taking notes/asking questions during appointments.

Your insurance may offer patient advocates/navigators or case managers who can provide support and help with things like scheduling appointments and obtaining needed approvals.

Peer-to-Peer Support

Some people also find it helpful to connect with others who are managing similar conditions and going through the same sorts of things. There are a variety of ways to connect with others who have had similar lived experiences.

♥ **ACHA Heart to Heart Peer Support Program**
empowermych.org/r/heart-to-heart

👤 **EmpowerMyCH Ambassadors**
empowermych.org/r/ambassadors

👤 **Team Uncle Joe Patient Navigators**
empowermych.org/r/team-uncle-joe

🗨️ **The Mighty - CHD Group**
empowermych.org/r/the-mighty

*Managing your health can take a toll on your emotional well-being. If you are feeling worn down, anxious, or low, ask your care team about emotional support. They can connect you with a social worker, counselor, or psychologist. For more ideas, see our **Mental Health Toolkit**.*

empowermych.org/r/mental-health-toolkit

Understanding Your Care Team

When you are an inpatient, you will likely meet two teams: the hospital medical team and the ACHD team. Not every hospital has both, and the ACHD team may not always be at your bedside. The hospital team may not contact the ACHD team on its own, so you can ask them to. You can also ask anyone which team they are on, to better understand their role in your care.

Full descriptions of each role are at the end of this guide, in **Care Team Roles, Defined**.

Two teams in the hospital

In the hospital you may meet two teams. They should be talking to each other. You can ask them to collaborate.



HOSPITAL TEAM

Attending, fellow, resident, intern
Advanced practice providers: nurse practitioners (NPs) and physician assistants (PAs)
Nurses and nursing assistants
Pharmacist
Therapists (PT, OT, RT)
Case manager, social worker



ACHD TEAM

ACHD cardiologist and fellow
ACHD surgeons and interventionalists
ACHD advanced practice providers: NPs and PAs
Nurses and social workers
Care coordinators and navigators
Psychologists

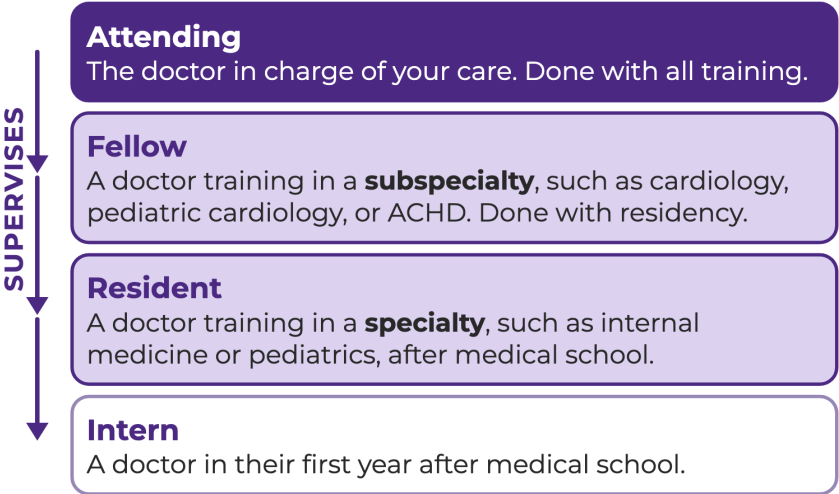


Ask: “Which team are you on?”

Sometimes your nurses or social workers are your biggest advocates.

Who is in charge of my care today?

You may meet a whole chain of doctors. Each one is supervised by the next one up. All are physicians (MD or DO).

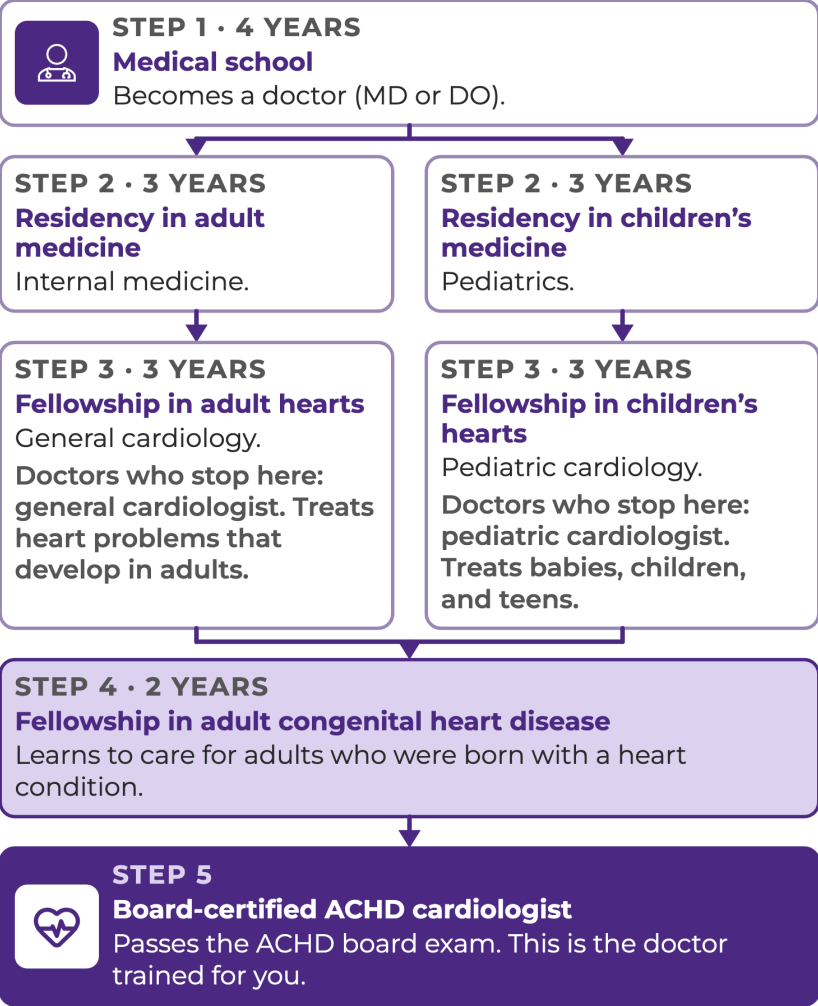


Ask: “Who is my attending today?”

Not sure who someone is? It is okay to ask.

How does a doctor become an ACHD cardiologist?

At least 12 years of training after college. Two paths lead there.



IT WAS DIFFERENT IN THE PAST

The ACHD board exam began in 2015. Many ACHD cardiologists trained before that and qualified through years of ACHD practice instead of step 4.

WHY IT MATTERS

People with CHD who see an ACHD cardiologist regularly are more likely to live longer and avoid complications.

Not every doctor who treats adults with CHD holds the certification, so it is fair to ask.

Ask: “Are you board certified in adult congenital heart disease?”

UNDERSTANDING YOUR CARE TEAM

To learn why seeing an ACHD cardiologist matters and how to find an ACHD team, see **Choosing My ACHD Team**.

empowermych.org/r/choosing-my-achd-team

Who else provides your direct care?

Look at the badge, then find it here.

ADVANCED PRACTICE PROVIDERS (APPS)



Nurse Practitioner
Advanced nursing degree. Can diagnose, order tests, and prescribe. Some states require physician supervision.



Physician Assistant
Training similar to a physician's, heavy on clinical hours. Provides care under physician supervision.

NURSES AND ASSISTANTS



Registered Nurse
Hands-on care. Provides and coordinates your care. Practices under their own license.



Licensed Vocational Nurse
Basic nursing care, such as vital signs and some medicines, under an RN or doctor. Called LPN in most states.



Certified Nursing Assistant
Bathing, eating, moving, and vital signs, under a nurse's direction. Often called PCA or PCT.



Medical Assistant
Mostly in clinics. Checks you in, takes vital signs, and helps during your visit. Not a nurse.

PHARMACY



Pharmacist
Dispenses your medicines, checks they are safe for you, and answers questions about them.

Not sure who someone is? It is okay to ask.

Who helps me get through the system?

Find the person whose job it is.

“I need help with discharge, an insurance approval, or getting to care.”



Case Manager

Plans your discharge and next level of care, works with your insurer on approvals, and lines up services after you leave.



Patient Navigator

Helps you past barriers to care: scheduling, transportation, paperwork, next steps. Part of a hospital, clinic, or nonprofit program.



Peer Navigator

A navigator who has lived with the same condition, trained to support others from that experience.

“I need someone to keep my appointments, tests, and referrals on track.”



Patient Care Coordinator

Schedules your appointments and tests, handles referrals, and keeps your providers in touch. Often your main contact at a specialty clinic.

“I’m struggling with money, housing, or how I’m coping.”



Social Worker

Mental health, housing, and help finding financial assistance.



Chaplain

Spiritual and emotional support for you and your family. Faith-based or not, as you prefer.

“I need someone on my side.”



Patient Advocate

Helps you understand your care, speak up, and work through the system. Some work only for you; others are employed by a hospital or insurer. You can ask who pays them, to better understand their role.

Advocates and navigators vary more than other roles. Not sure who to go to? It is okay to ask.

Who do I ask about...?

Bills and records.

“...a bill, a payment plan, or a denial.”



Billing / Accounting

Files your insurance claims and handles bills. Can set up a payment plan or help with a denial.

“...getting or sending my records.”



Medical Records Office

Keeps your records and processes releases when you, a provider, or an insurer asks.

Not sure who to go to? It is okay to ask.



PEER EMPOWERMENT

Shelley Truskowski

Heart Block, Atrial Septal Defect

“

I remember being in the hospital after having a pacemaker lead extraction surgery. This surgery was late on Friday. Over the weekend, I started noticing an unusual feeling in my chest and knew something was wrong. I told every nurse who came into my room, but they kept making me feel like I was imagining it. I felt unheard and dismissed until a really caring nurse showed up Sunday morning. She asked how I was doing as she opened the curtains in my room. I felt defeated at that point and told her I didn't think she would believe me. She encouraged me to tell her. I told her the same thing I had told all the other nurses all weekend. She gave me some of the best advice and I still remember it after all these years. She reassured me that she did believe me. She told me nobody knows your body better than you. She was right. My electrophysiologist came in Monday and scheduled me for another pacemaker lead surgery first thing that morning. ”

Something went wrong with my care. Who can help?

All three help patients. They do not all work for the same people, and that changes what they can do for you.

WHO THEY WORK FOR

WORKS FOR THE HOSPITAL



Patient Relations

Start here with a concern or complaint about your care. They help sort it out and can explain your rights. Staff are often called Patient Representatives.

THE HOSPITAL, OR THE GOVERNMENT



Ombudsman

Some hospitals call their complaint office the Ombudsman instead of Patient Relations. Outside hospitals, the government has ombudsmen for people in nursing homes and for people on Medicare.

YOU, A HOSPITAL, OR INSURER



Patient Advocate

Helps you understand your care and speak up. If you want someone whose only job is to help you, choose an independent advocate: you hire them, or a nonprofit provides one free.

WHY IT MATTERS

Someone paid by the hospital helps you within the hospital's rules. Someone paid by you answers only to you.

Ask anyone who offers to help: “Do you work for the hospital, or for me?”

Shared Decision-Making

Healthcare isn't happening *to you*. It should be happening *with you*. When it comes to receiving care and working with your providers, it is a team approach.

While your providers have extensive knowledge of your condition, **you are the expert on your own body**. When you are making a medical decision (such as a medication change or a possible surgery), shared decision-making is essential.

Working Together As A Team

Shared decision-making is you and your provider(s) making a medical decision together that feels right to you. This includes having an open discussion about your situation and a space where you can ask questions. You may also be able to bring in a social worker or other person to help you communicate what you need.

This is especially important for long-term management of chronic illness.

A lot of patients with CHD have multiple conditions (comorbidities), and that can require multidisciplinary care. However, providers may not communicate with each other unless you ask them to. You can take the lead: ask each provider to send their notes and test results to your other providers, and keep your own copies to share at your next appointment.

Know Who To Contact

Make sure to ask who your point of contact is for your ACHD care and how you should reach them for general questions and in case of more urgent situations. This also applies to other specialists and care teams.

Save contact info in your phone for your key providers and clinics.

Importance Of Online Patient Portals (MyChart)

Online patient portals, like MyChart, are important tools for navigating your care effectively. You can see information for your upcoming appointments, your list of prescribed medications and request refills, access labs and other records, make payments, and message your healthcare team.

If the portal or other technology feels hard to use, you are not alone. Ask your clinic for help. A social worker can often help you set up your account and learn how to use it.

Tips for Using Your Patient Portal Effectively

If someone other than your doctor responds to your message and the response isn't sufficient, you can ask for your physician to answer your question directly.

If you don't hear back, how long should you wait? You may receive an automated response stating that you should hear back within a set number of days. If it is urgent, you can follow up with another message or with a phone call.

Scheduling systems differ from place to place. If calling is an option, call. Unfortunately, you sometimes just have to be persistent.



PEER EMPOWERMENT

Ana Cecilia Gonzalez

Transposition, Double Inlet Left Ventricle

“

After my first ablation, I kept waiting for my atrial flutter to stop, but it didn't. My doctors asked me to be patient, but I was miserable—the arrhythmia was keeping me from enjoying my life. After several conversations, they understood that waiting was no longer working for me and that I needed another ablation. At the same time, I wasn't emotionally ready to go through another procedure. They gave me the time I needed without pressuring me. When I finally said, 'I'm ready,' they immediately moved forward with my second ablation. That experience taught me that shared decision-making means speaking up about how a condition is affecting your life, while also having a healthcare team that listens and respects when you are ready to move forward. ”

Patients can feel that how nice they are to their providers affects their care. Not wanting to feel like a burden, or like you are being “non-compliant,” is normal. **It’s okay to advocate for yourself and ask questions.** It may be helpful to use a simple template when sending messages to your provider or when asking questions during an appointment.



TRY THIS

Ask Me 3

Ask Me 3 is a three-question template from the **Institute for Healthcare Improvement**. Ask them at every appointment, or use them to shape a message to your provider³.

- 1 What is my main problem?
- 2 What do I need to do?
- 3 Why is it important for me to do this?

Listening – It Goes Both Ways

Communication goes both ways. It helps when you and your providers understand what to expect from each other: the best way to reach them, how soon you should hear back, and what they need to know from you. If you are not sure, ask: “What is the best way to reach you, and when should I expect to hear back?”

Types Of Questions To Ask

- ◆ What is the diagnosis?
- ◆ What does this diagnosis/treatment mean for me and my daily life?
- ◆ What are the treatment/medication options? How do they differ? What sort of side effects should I expect?
- ◆ What sort of symptoms/changes should I make sure to contact you about? And how should I contact you?
- ◆ Do I need to see a specialist or other type of provider?
- ◆ Do we need to schedule a follow-up appointment? If yes, can I do that today before I leave?

Medical Interpretation

If you feel more comfortable speaking a different language, including sign language(s), **you have a legal right to a professional medical interpreter in all medical settings** (inpatient, outpatient, clinic visits, Emergency Room, etc.). If you know you will need an interpreter for an upcoming appointment, you can let the clinic know in advance to ensure one is available.

Some important notes on medical interpreters:

- ◆ Even if a family member or friend can translate, a trained medical interpreter helps make sure everything is communicated the way it needs to be and nothing is lost in translation. Your loved ones can still be there for support.
- ◆ Might be in person, over the phone, or via video call
- ◆ You cannot be charged for medical interpreter services
- ◆ Medical interpreters are subject to the same confidentiality and privacy protections as clinicians (HIPAA)
- ◆ Protected under Title VI of the Civil Rights Act and Section 1557 of the Affordable Care Act

Finding Treatment That Works For You

There are many considerations when deciding on a treatment plan. A few things to keep in mind:

Key questions for your provider

- ◆ Is my treatment working?
- ◆ Are you seeing the results you wanted?
- ◆ What should I expect with this treatment?

How does it make you FEEL?

- ◆ Once you start a new treatment or medication, keep track of new symptoms/side effects.
- ◆ There is often a period of time you need to wait to adjust to the treatment and see the effect.

Inform your provider if you're experiencing side effects.

- ◆ If a medication is causing unpleasant or disruptive side effects (nausea, insomnia, GI issues, changes in your ability to pay attention, etc.), tell your provider.
- ◆ Other treatments, like medical devices and procedures, may also come with side effects or impacts.

Make sure to communicate any changes you experience to your provider. Some may be important for them to know about, and you may be able to find something together that works better for you.

How to have conversations around these topics

- ◆ Speak up if you feel like the treatment isn't right for you or if you need something different. You know your body, and what works for you and what doesn't.
- ◆ Ask for an alternative treatment plan if what you're doing now isn't working well for you.
- ◆ There may be a variety of options. To find the best fit, discuss with your provider or healthcare team how each one works and what it will do.
- ◆ When deciding on a treatment, it is important to consider the risks and benefits of that treatment. Some treatments may have side effects, which you should discuss with your provider. You should decide whatever is best for you, which may be different from what someone else might decide.



PEER EMPOWERMENT

Ana Cecilia Gonzalez

Transposition, Double Inlet Left Ventricle

“

Recently, I was experiencing frequent arrhythmias, but I kept feeling that something else was going on. I listened to my body and continued looking for an answer. A sleep study revealed that my oxygen levels were dropping severely during the night, at times into the low 80s. I shared those results with my heart team, and they listened. They supported treating the nighttime oxygen problem, and since then my flutter and tachycardia have improved significantly.

For me, this was another reminder of why we have to advocate for ourselves. Our doctors bring their medical expertise, but we live in our bodies every day. Sometimes we know that something is different before we know exactly what it is. Speak up, ask questions, and keep looking for answers—and when you have a healthcare team that truly listens, you can work together to find them. ”



EMPOWERMENT

It is OK to ask questions and share concerns. If you don't understand something, ask for clarification or ask your provider to explain it differently.

Seeking Second Opinions

What is a 'second opinion'?

A second opinion is when another doctor reviews your medical records and provides their recommended course of action, which may be a medication, surgery, or other treatment.

Second opinions are intended to give you more information. You don't have to do what the second opinion recommends. You may decide that your first doctor's recommendation is actually better for you. Or, you may even want to get a third opinion.

Why do people get second opinions?

There are many reasons why a patient may seek a second opinion. In some cases, insurance may require a second opinion to confirm the recommended course of treatment. Doctors may also recommend seeking another opinion if they think it would be helpful for their patient.

Otherwise, patients always have the right to see another doctor to confirm a diagnosis or treatment plan. You may decide to get a second opinion for many reasons, including:

- ◆ Your provider has suggested it, or knows another place that offers care or treatment they cannot provide
- ◆ You want to explore other treatment options
- ◆ Your current provider isn't a good fit for you



CLINICIAN EMPOWERMENT

Mark Norris, MD, MS

ACHD Cardiologist

“

Second opinions are a welcome topic in my clinic, and they can be a healthy part of a cardiac care plan. Sometimes I as the cardiologist am the one suggesting a second opinion. For difficult decisions and complex care plans, it can be useful to have another perspective. Often both the patient and I learn something from the ACHD team reviewing the situation. I want my patients to feel comfortable bringing up this option, and then I can help direct them to a center and team who are experts in this issue so that the time and investment in a second opinion is worthwhile. ”

How do you get a second opinion?

It is your right as a patient to seek a second opinion if you want one. Like many things in healthcare, how you go about it often depends on your medical insurance.

- 1 Check with your insurance.** If you want to see a doctor at a different clinic or healthcare institution, your insurance may require a referral (this is common with HMO plans).
- 2 Choose where to go.** You may be able to see another doctor at the same clinic, which is less likely to require a referral but may require approval from your insurance or from the clinic itself. Some healthcare systems also have dedicated second-opinion programs, which may charge a flat fee (not necessarily connected to your insurance).
- 3 Share your records.** Make sure the new doctor has:
 - ◆ lab results
 - ◆ scans/imaging
 - ◆ medications
 - ◆ surgery/hospital reports (if applicable)
 - ◆ your current doctor's assessment and plan
 - ◆ any specific questions you have

- 4 Decide what's next.** After a second opinion, you may stay with your original doctor for ongoing management of your conditions, or you may be able to switch doctors, depending on the situation and what you want to do.



EMPOWERMENT

Getting another opinion on your care and going through the process of essentially repeating appointments can be a lot of work for a patient to navigate. Do whatever is best for you.

Advocating for Yourself

You know your body better than anyone else, and advocating for yourself can help you get the care you need. It's important to communicate in ways that help make that happen.

Educate Yourself

The better you understand your conditions, the better you can communicate with your providers and advocate for yourself.

If health information or the healthcare system ever feels hard to understand, you are not alone. Only 12% of adults in the U.S. have the skills to easily find, understand, and use health information and services. These skills are called *health literacy*⁴.

→ Learn More About Your Health

EmpowerMyCH's ACHD resources are patient guides to living with adult congenital heart disease.

Explore ACHD Resources

empowermych.org/r/resources

Making the Most of Your Appointments

Often, you have to wait a while (weeks or even months) for an appointment. To make the most of your appointments, it is important to come prepared.

Preparing Before Your Appointment

- 1 Write down a list of questions and concerns before your appointment.
 - ◆ Have a primary goal for what you want or need from the appointment (this also applies to messages you send to providers).⁵
 - ◆ State your concerns, even if they don't feel like a "problem"
 - ◆ State your questions, even if they feel unrelated. No question is a bad question.
 - ◆ What you need from them
- 2 Have your insurance information on hand.
- 3 Bring/have access to your calendar so you can schedule any needed future appointments before leaving.
- 4 Ask whether a virtual visit (by video or phone) is an option, especially if getting to the clinic is hard.



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Consider bringing a close friend or family member with you to your appointment.



PEER EMPOWERMENT

Kimberly Payton

Patient Parent & Advocate

“

Patients rely on providers not only for medical attention, but also for information, advice, and consolation. Therefore, strong communication with patients is paramount in maintaining positive patient relationships. ”

During Your Appointment:

- 1 Take notes about what your provider says, or ask a friend or family member to take notes for you.
- 2 Ask for your provider's contact information and their preferred method of communication. Ask how to reach them outside standard working hours (nights and weekends).

Remember that nurses and pharmacists are also good sources of information.

After Your Appointment:

- 1 Schedule any needed future appointments before leaving.
- 2 If any blood tests were ordered, you may be able to get them done on-site before you go home, so you don't have to come back just to do them later.
- 3 Learn how to access your medical records, so you can keep track of test results, diagnoses, treatment plans, and medications, and prepare for your next appointment.

Care Team Roles, Defined

Note: Different hospitals/clinics/healthcare systems may do things a little differently, use different terminology, or offer additional services. The following are descriptions of some healthcare professionals you may encounter, but these may differ slightly depending on where you receive your care.

Different Terms You May Hear For Physicians/Doctors

Physician: A general term for a medically trained doctor, having obtained either a Doctor of Medicine (MD) or Doctor of Osteopathy (DO) degree.

Attending: Has finished all training and is the doctor responsible for your care. In a teaching hospital, the attending also supervises the residents and fellows on your team.

Fellow: Has completed their specialty training as a resident and is pursuing further specialty training as part of a fellowship to obtain more advanced, specialized skills. They can provide care independently, but are supervised by an attending for their subspecialty.

Resident: A doctor in residency, the specialty training after medical school (usually 3 to 7 years). Residents treat patients under an attending's supervision.

Intern: Has recently graduated from medical school. Provides medical care, but under supervision.

Types Of Cardiologists You May Encounter

General Cardiologist: A physician who has completed a general cardiology fellowship as well as an internal medicine residency. They typically treat acquired cardiovascular conditions among adults, such as high blood pressure, coronary artery disease, and high cholesterol.

Pediatric Cardiologist: A physician who has completed a pediatric cardiology fellowship as well as a pediatrics residency. They focus on heart conditions among babies, children, and adolescents, which are typically congenital defects.

ACHD Cardiologist: A general or pediatric cardiologist with extra training in adult congenital heart disease. Since 2015, doctors can earn board certification in ACHD. Newer ACHD cardiologists complete a two-year ACHD fellowship; many who trained earlier qualified through years of ACHD practice. Not every doctor who treats adults with CHD holds ACHD board certification from the American Board of Internal Medicine or the American Board of Pediatrics, so it is fair to ask.

Other Types Of Clinicians Who Provide Direct Clinical Care

Nurse practitioners and physician assistants are often called **advanced practice providers (APPs)**.

Nurse Practitioner (NP): Have advanced nursing degrees and often work within a specific medical specialty. They can do many of the same things a doctor/physician can, including diagnosing conditions, ordering tests, and prescribing medications, but they undergo different training. Some U.S. states require NPs to be supervised by a physician. Also called an Advanced Practice Registered Nurse (APRN).

Physician Assistant (PA): Have similarities to the training physicians receive, with a heavy focus on clinical rotation hours. They typically provide patient care under the supervision of a physician (MD/DO) and have more general training, rather than focusing on a medical specialty.

Registered Nurse (RN): Have a nursing degree and a state license. They are very hands-on in providing and coordinating patient care and have the option to focus on a medical specialty. Nurses practice under their own license and report to nurse leaders.

Licensed Vocational Nurse (LVN): Completed a one-year nursing program and a state licensing exam. Provides basic nursing care, such as taking vital signs, giving some medications, and changing dressings, under the direction of a registered nurse or doctor. Called a Licensed Practical Nurse (LPN) in most states.

Certified Nursing Assistant (CNA): Completed a short training program and state exam. Helps with bathing, eating, and moving, and takes vital signs, under a nurse's direction. Hospitals often call this job Patient Care Assistant or Technician (PCA/PCT).

Medical Assistant (MA): Completed a short training program and is often certified. Works mostly in clinics: checks you in, takes vital signs, reviews your medications and history, and helps the doctor during your visit. Medical assistants are not nurses.

Pharmacists: Receive a degree in pharmacy and are responsible for dispensing prescribed medications, confirming medication safety for patients, and providing counseling to patients related to their medications. May collaborate more directly with prescribers, especially in inpatient settings.

Types Of Therapists That Help Your Body Function Better

Physical Therapist: Focuses on strengthening and healing the body for improved mobility.

Occupational Therapist: Focuses on helping patients with their physical ability to complete tasks they need in their day-to-day lives.

Respiratory Therapist: Helps patients with their breathing by assessing lung capacity and blood oxygen levels, administering treatments to improve breathing, and educating patients on how to use inhalers and home oxygen properly.

Provide More Practical/Logistical Support

Case Manager: In a hospital, plans your discharge and next level of care, works with your insurer on approvals, and lines up services after you leave, such as home health, rehab, or equipment. Usually a nurse or social worker. Insurers employ case managers too.

Patient Care Coordinator: Helps organize your care, such as scheduling appointments and tests, handling referrals, and making sure your providers share information. Often your main contact at a specialty clinic, such as an ACHD program. Sometimes a nurse.

Social Worker: Helps patients with psychosocial and socioeconomic needs, such as mental health, housing, and securing financial assistance.

Chaplain: Provides spiritual and emotional support to patients and their families, which can (but does not have to be) related to a specific religion/faith, based on what the patient/family desires.

Patient Advocate: Helps you understand your care, speak up, and work through the health care system. Some advocates work only for you: you hire and pay them, or a nonprofit provides one for free. Others are employed by a hospital or an insurance company; the hospital's version is often called a Patient Representative. A good advocate will tell you who pays them and where their duties could conflict. If you want someone with no ties to your hospital or insurer, ask for an independent patient advocate. Look for the BCPA credential (Board Certified Patient Advocate).

Patient Navigator: Helps you get past barriers to care, such as scheduling, transportation, paperwork, and next steps. Usually part of a hospital, clinic, or nonprofit program.

Peer Navigator: A navigator who has lived with the same condition and is trained to support others from that experience.

Note: Advocates/Navigators may vary more than some other, more standardized roles.

More Roles To Be Aware Of Within The Healthcare System

Billing/Accounting: Responsible for filing insurance claims based on clinical care records and for overseeing patient billing and payment. They can sometimes help establish payment plans or assist with navigating insurance denials.

Medical Records Office (Health Information Management, or HIM): Manages patient records and ensures proper documentation of clinical care. It is also responsible for processing record releases when a patient, provider, or insurance company requests them.

Patient Relations: Usually a department within a healthcare institution that helps patients address concerns or complaints related to their care. They are responsible for upholding patients' legal rights and facilitating communication between patients/their families and the healthcare system. Those who work in Patient Relations are often called "Patient Representatives."

Ombudsman: The word means different things. At some hospitals, the Ombudsman Office is the hospital's own complaint office, like Patient Relations. Outside hospitals, every state has a Long-Term Care Ombudsman, a government-funded advocate for people in nursing homes and assisted living, and Medicare has a Beneficiary Ombudsman for Medicare complaints.

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