

Empower

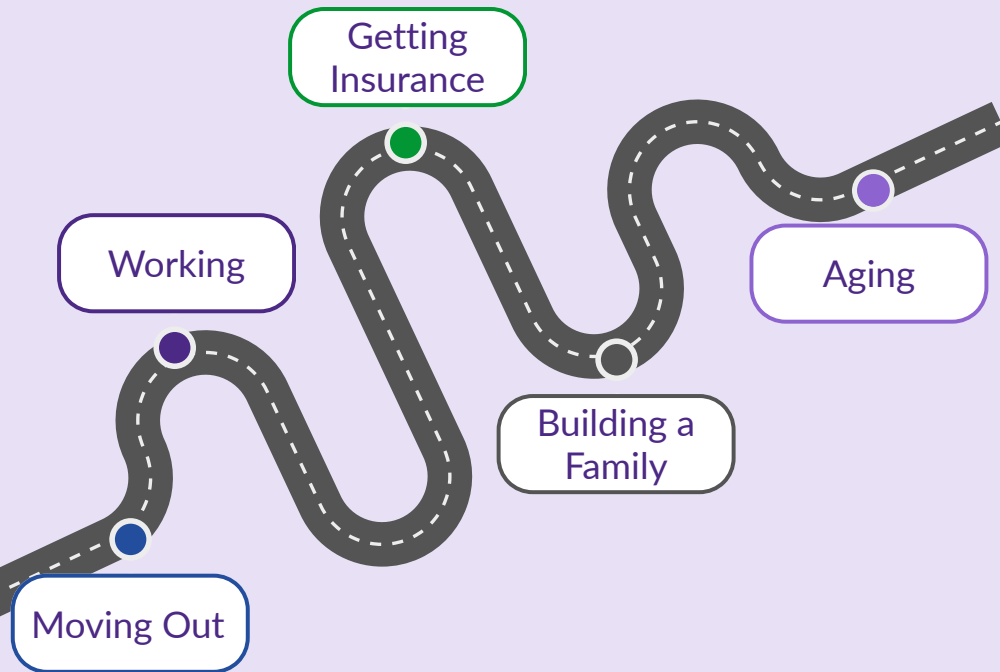
Understand

Thrive



EMPOWER
MY CONGENITAL HEART

Going Through Life with CHD



A NOTE ON THIS SET OF INFORMATIONAL MATERIAL




EmpowerMyCH has users across all age groups, from adult teenagers to people in their 80s.

Knowing how to manage your CHD condition throughout your life is essential to maintaining your health and living life to the fullest.

The material here will cover various life stages. This means **not every section will apply to you in your current life stage.**

Please let us know if there is additional information based on the experiences you've already had in your life that would be helpful for us to include for others.





YOUR NEXT CHAPTER

Becoming an adult can feel exciting, overwhelming, or both. **Whatever you're feeling, that's okay.** Over time, managing your care will gradually shift more into your hands. You don't have to figure it all out at once.

As you take on more of your own care, here are some things you'll start to get comfortable with:

- ◆ Ordering and refilling your medications.
- ◆ Scheduling and keep track of your appointments.
- ◆ Recognizing and tracking your symptoms.
- ◆ Creating a daily routine that balances your health and life.
- ◆ Learn about your specific heart condition.



Listen to Your Body!

It is important to learn how to balance activity, stress, and rest.

YOUR NEXT CHAPTER



Before You Leave

Your next chapter might mean college, work, or something else entirely. Whether you're staying close to home or moving far away, a few simple steps now can help keep your heart health a top priority.



Stay Heart Healthy:

- I know the name of my heart condition.
- I can describe my condition to a healthcare provider, or have it written down and easy to access.
- I can schedule and manage my own medical appointments.
- I know how to track my symptoms and when to reach out to my care team.
- I know how to access copies of my medical records.
- I know how to use an online patient portal.
- I know how alcohol, recreational substances, and certain medications can interact with my heart condition.



In Case of Emergency:

- I know where the nearest hospital and ER are.
- I know where the nearest ACHD center is, or how to reach my ACHD care team in an emergency.
- I have a summary of my condition that I can share in an emergency.
The EmpowerMyCH Digital Medical Passport is a great tool for this.
- My roommate or trusted friend knows about my condition.
- I know when to call my care team versus when to go to the ER.



Medication & Pharmacy:

- I know my medications, doses, and schedule.
- I can order and refill my own prescriptions.
- I know how to store my medications properly.
- I understand how my medications can interact with other drugs, supplements, and alcohol.



PEER EMPOWERMENT

Shawn, Patient with Tetralogy of Fallot

“Take an early and active role in your congenital heart journey (learn your diagnosis, surgeries, medicines, etc) at an early age.”



Using My Resources:

- I am registered with the campus or workplace disability and accessibility services (if applicable).
- I know what accommodations are available to me and how to request them.
- I have a manageable school or work schedule that supports my health.
- I know about vocational rehabilitation services and whether they may be available to me.



Empowerment

When completing paperwork for college, you may be asked if you want to enroll in the college's student health insurance plan.

This can be a good option for you if you aren't able to stay on your parents' healthcare plan or don't have an insurance plan.



MOVING SOMEWHERE NEW

Establishing Care

Establishing healthcare in a new city can take time and thoughtful planning.

If possible, **schedule** your first appointment with a new cardiologist **before you move** so there is no gap in your care.

To locate the nearest ACHA clinic, visit the **clinic directory** created by the Adult Congenital Heart Association.



Resource: ACHA Directory
<https://bit.ly/ACHA-Clinic-Directory>

When moving, your insurance coverage may change if:

- ◆ You get a new job.
- ◆ You are moving to a new state.
- ◆ You are relocating to an area with different in-network provider availability.



Transferring Prescriptions to a New Pharmacy

If you are moving to a new city, **start by contacting the pharmacy** where you plan to fill your prescriptions. Let them know you would like to transfer your prescriptions from your current pharmacy.

They will typically coordinate the transfer but may ask you for some information to help the process run smoothly

Be prepared to provide:

- ◆ Your full name and date of birth.
- ◆ Your name, phone number, and address of your current pharmacy.
- ◆ The names of the prescriptions you are transferring.
- ◆ Your insurance information.

MOVING



Transferring Medical Records

Your new care team **will need your full B medical records** to provide the best care. Even if your current and new hospitals use the same platform, like MyChart, you may still need to request that your records be transferred.

This helps ensure your new providers have a complete understanding of your medical history and care.

Steps to transfer your medical records

- ◆ Contact your NEW provider and confirm: Name, phone number, and address.
- ◆ Contact your CURRENT provider and ask about their process. They may start the process for you or ask you to sign a medical records release form.
- ◆ Complete the authorization form. It is important to fill out the form completely, including the description of what medical records you want such as full records, , labs, imaging or records from the last two years.



Empowerment

Processing a medical records release form can take time. It is important to request your records several weeks in advance so your new medical team receives them before your first appointment.

In addition to transferring your medical records, keep a digital copy of your care summary and surgery notes. If you would like a copy of your medical records, it is your right as a patient, but you usually have to submit a request to receive them.



PEER EMPOWERMENT

Lindsay Alano, Heart & Liver Transplant Recipient (Former CHD Patient)

“ When I was preparing to move from Hawaii to Maryland, I was going through a lot with my CHD. It motivated me to set up my care in advance. I found an ACHD specialist, coordinated the transfer of my medical records to my new cardiologist, and scheduled my initial appointment before moving. Knowing everything was in place gave me peace of mind and ensured there wouldn't be a lapse in my care.



GETTING YOUR OWN HEALTH INSURANCE

People may leave their parents' insurance or need to get their own plan at different times. Some may stay on their parents' plan through their mid-20s.

Some important terms:

Open Enrollment: Designated annual period when you can sign up for, renew, or change health insurance plans.

Marketplace: A government-run website where you can compare private health insurance plans and enroll in a plan (a.k.a. Health Insurance Marketplace, or Exchange).

HMO (Health Maintenance Organization): A type of health insurance plan that requires selecting a primary care physician who then provides referrals to specialists.

PPO (Preferred Provider Organization): A type of health insurance plan with a network of providers; does not require referrals.

Referral: A written order, often from a primary care provider, that authorizes the patient to see a specialist or receive specialized services; required by HMO plans.

In-Network: Providers who have contracted with your insurance; will be less expensive.

Out-of-Network: Providers who are NOT contracted with your insurance; will be more expensive.



GETTING YOUR OWN HEALTH INSURANCE

Deductible: A pre-specified amount of money you pay out-of-pocket for medical services before insurance starts to contribute.

Copay (copayment): A fixed fee you pay for specific medical services, including prescription medications.

Out-of-Pocket Maximum: The most you will be required to pay for covered medical services each year.

Coinsurance: A specified percentage of the cost for a covered medical service that you will have to pay (ex: 20%), while your insurance pays the remaining percentage; starts after your deductible.

Pre-Authorization: An approval process that insurance may require for specific services before the service can be provided (a.k.a. prior authorization, pre-approval, pre-certification).

FSA (Flexible Spending Account): Employer-provided account where you contribute pre-tax funds towards medical costs; must use funds by the end of the year or you lose them.

HSA (Health Savings Account): Employee-owned account for pre-tax funds set aside for medical expenses; funds do not expire.



GETTING YOUR OWN HEALTH INSURANCE

Choosing your plan

Private Plan

If you prefer to buy your own coverage, you can purchase a private insurance plan. Private medical insurance can only be purchased through the Marketplace or directly from an insurance company.

Employer-Sponsored

Depending on your employer, you may qualify for medical benefits through your job. It is important to understand the different options, as they can affect the cost of your annual visits, tests, procedures, and medications.

Medicare/Medicaid

Medicare and Medicaid have specific eligibility rules and requirements.

Marriage

If your spouse receives medical benefits through their employer, you may be able to be added to their plan.

GETTING YOUR OWN HEALTH INSURANCE



What is Open Enrollment?

The Open Enrollment period **usually starts in the fall** and allows you to **explore different insurance options** offered through the Health Insurance Marketplace, employer-sponsored plans, or Medicare.

During Open Enrollment, you can:

- ◆ **Assess** your healthcare needs.
- ◆ **Compare** plan benefits, premiums, and out-of-pocket costs.
- ◆ **Select** the coverage that best suits your needs and budget.

Resource:



Health Insurance Information
Curated for those with CHD
bit.ly/acha-insurance

GETTING YOUR OWN HEALTH INSURANCE



High Deductible vs. Low Deductible?

High-Deductible Plan

- ◆ Lower monthly payment (premium).
- ◆ **You pay more up front** before insurance kicks in.
- ◆ It may be a good choice if you **don't expect much care** and want to save on premiums.
- ◆ Often comes with a Health Savings Account (HSA).
- ◆ Costs can be **less predictable** — you may face large bills if unexpected care is needed.

Low-Deductible Plan

- ◆ Higher monthly payment (premium).
- ◆ **Insurance pays sooner**, so you pay less when you get care.
- ◆ It may be a good choice if **you expect** frequent visits, costly tests (like MRIs), or procedures/surgeries.
- ◆ **More predictable** costs.

GETTING YOUR OWN HEALTH INSURANCE



Vision and dental care typically require separate insurance plans. These may also be employer-sponsored, private, or purchased on the Marketplace, either individually or in a combined (vision+dental) supplemental plan.

Vision Insurance

Covers routine eye exams and usually provides an allowance of funds for prescription glasses or contacts. Treatment of other eye-related problems, such as cataracts, glaucoma, and cancer would be covered under your general health insurance. Options include: Vision Benefit Plans (PPO/HMO), and Vision Discount Plans.

Dental Insurance

Covers routine dental exams, x-rays, cleanings, treatment for cavities and root canals, and some minor surgical procedures. Options include: Dental Benefits Plans (PPO/HMO), Dental Indemnity, and Discount Dental / Dental Savings Plans.

Routine dental care and cleanings are essential for those with CHD to avoid endocarditis (heart infection).

Alternative options can include: cash payment, setting up payment plans, sliding scale, or getting care at dental schools and/or optometry (eye) schools.



CAREER

Selecting your Insurance Plan

We just went over the details of choosing an insurance policy. If applicable, make sure you understand the options your employer offers.

If your workplace offers **short- and long-term disability insurance**, it is important to consider enrolling in these benefits carefully. Short-term and long-term disability insurance can provide income protection if you are unable to work for a period of time due to your congenital heart disease (i.e., open-heart surgery or a transplant).

Hospital indemnity insurance is a type of supplemental coverage that pays a fixed, direct cash benefit if you are admitted to the hospital. This can help cover the cost of daily expenses, deductibles, and copays. It works alongside, not instead of, your primary health insurance, paying per day or per stay.



Empowerment

Your employer may have **benefits specialists** you can talk to or may provide informational sessions where you can learn more. These can be helpful for making a decision.



Americans with Disabilities Act (ADA) Considerations

The Americans with Disabilities Act (ADA) protects people from discrimination in many areas of life, including employment.

This **ensures that people with disabilities have equal opportunities** to get and keep a job and be successful in the workplace.

How can ADA help in the workplace?

ADA gives you the right to request **reasonable accommodation** (changes) in the workplace (or at home, if remote work) to help you do your job.

Examples of accommodations for those with CHD:

- ◆ Flexible hours for medical appointments
- ◆ Extra break for fatigue
- ◆ Temporary reduced workload after a surgery or procedure
- ◆ A quiet place to rest if symptoms flare
- ◆ Limiting heavy lifting

CAREER



When can I request an accommodation in the workplace?

There's no single 'right time' to request an accommodation. You can ask whenever you need support.

Here are some common situations where you may need to request accommodations:

- ◆ After you receive a job offer
- ◆ When you start a new job
- ◆ When your health needs change
- ◆ After being hospitalized or after a surgery



Empowerment

When you are requesting accommodation in the workplace, **you DO NOT have to give your entire medical history.** Your employer can only ask for information relevant to your ability to do the job.



FAMILY PLANNING

Families come in all shapes and sizes.

It is important to talk to your ACHD doctor when choosing what will work best for you.

This may be a natural pregnancy, IVF, surrogacy, adoption, or even choosing to build your family without a child.

Family planning is deeply personal. You can create a beautiful family regardless of whether, or how, you have children.



FAMILY PLANNING

If you choose to pursue pregnancy, some things to keep in mind:

Before you start planning your pregnancy, make an appointment **with your ACHD specialist** to discuss options.

You may also have access to a dedicated family planning team designed for patients who have chronic illnesses and/or may have higher risk pregnancies.

Pregnancy has a major impact on your body, including your heart. **Different people have different risks** with pregnancy.

There are also **OBGYNs who specialize** in higher-risk patients, which your ACHD specialist may recommend when establishing obstetric care.

It is also important to **know which medications may be unsafe** during pregnancy.



Resource from ACHA:
<https://bit.ly/CHD-Pregnancy>

FAMILY PLANNING:

Adoption



Meagan's Story (HLHS)

Meagan has hypoplastic left heart syndrome.

Our path to becoming parents didn't follow the timeline we imagined. After being approved to try to get pregnant, we found ourselves facing many unknowns and difficult conversations about what the future might look like. Through those honest talks, we realized that **adoption felt like the right path for our family.**

We spent several months researching agencies, processes, and stories from other adoptive families. It was a season filled with questions, learning, and a lot of trusting our instincts. Ultimately, we **chose to work with a lawyer who also facilitated matches** with expectant mothers. In May of 2023, we officially signed with our lawyer, and the waiting began.

Over time, we were presented with several different situations. Each one came with hope, nerves, and the possibility that it could be the one. But in the end, we were not chosen. It was emotional and sometimes discouraging, yet we kept believing that the right situation would come. Then, in September of 2023, everything changed. **We were matched.**

Suddenly, the process that had felt so uncertain became incredibly real. We learned the baby's gender and received ultrasound photos.

FAMILY PLANNING:

Adoption

Meagan's Story ***(HLHS)***



Seeing those tiny images for the first time was surreal and overwhelming in the best possible way. **This little life, whom we had been hoping and waiting for, was on the way.**

In January of 2024, our son was born. One of the most meaningful parts of the experience was meeting his birth mother and getting to know her more. The love and strength she showed in those moments are something we will always carry with us. The next day, our lawyer arrived to complete the initial legal steps, **marking the beginning of our life together.**

Finally, in April of 2024, everything became official. Our son was legally and forever ours. The journey to him was a rollercoaster of emotions: hope, waiting, disappointment, joy, and overwhelming gratitude.

Adoption changed our lives in ways we could never have imagined. We are endlessly thankful for adoption, for his incredible birth mother, and most of all for our son, who made us a family.

For anyone considering adoption, our biggest advice is to be patient and trust the process. There may be moments of uncertainty and waiting that feel endless, but the right story can unfold in ways you never expect. **Keep asking questions, trust your instincts, and hold onto hope.**

FAMILY PLANNING: IVF/Surrogacy



Brittney's Story (DILV, Fontan)

Brittney was born with Double Inlet Left Ventricle and had the Fontan at 3 years old, and then two more open heart surgeries at 6 and 15.

I have known that I was meant to be a mom for as long as I can remember. I even chose to be a teacher because I knew it would be the perfect job to have while also being a mother.

When my husband and I got engaged, **my cardiologist invited us to his office to discuss pregnancy.** He explained that it was extremely high risk for both myself and my baby.

My husband and I decided that we couldn't risk my life or our baby's. If I was going to be a mom, I wanted to be the strongest, healthiest version of myself that I could be. I wanted to be able to run and play and carry my kids for as long as I possibly could. **Although I was sad to give up carrying my babies in my belly, carrying them in my arms was far more important.**

This is when I threw myself into researching **alternative ways to motherhood**--adoption and gestational surrogacy being the main two. Both came with different risks, difficulties, and financial strains. Ultimately, we decided to pursue **surrogacy.**

FAMILY PLANNING: IVF/Surrogacy



Brittney's Story (DILV, Fontan)

As soon as we got married in 2019, **we started in vitro fertilization (IVF)**. My fertility doctor and cardiologist worked together to ensure my safety. I ended up doing two rounds of IVF, and my heart was fine throughout the process.

I then took to the internet and found the most amazing woman and friend of a lifetime, who **offered to carry my precious embryo for me**. She will always be like family to us, and I will never be able to express my gratitude for her.

We were blessed with the most perfect baby boy! **My life and heart were changed forever** in ways I could never have even imagined. I kept thinking about what would happen to him when my husband and I were gone one day, though, and I knew I needed to give him a sibling.

By the grace of God, a friend of mine let me know that she **was interested in being a gestational surrogate** and so selflessly offered to carry our second son for us.

Seeing my boys together is indescribable. Their bond and love for each other are like nothing I have experienced. It's so crazy to think I made both of them at the same time in the IVF lab, too! Science is so amazing.

FAMILY PLANNING: IVF/Surrogacy



Brittney's Story (DILV, Fontan)

We used all our embryos, but we are still open to the possibility of adopting in the future. My **advice to anyone with CHD who is considering surrogacy is to do SO much research.** Try and be open with your friends and family that you are looking into surrogacy because you never know who you might inspire or who is already interested in becoming a surrogate!

Lastly, I also know that when you first look into surrogacy online, it can seem overwhelmingly expensive and out of reach. However, **it doesn't necessarily have to be that way.** By thoughtfully navigating the process like we did, such as working independently rather than through an agency and making intentional, informed choices along the way, the overall cost can be significantly reduced and comparable to adoption.

While every journey is unique, it's not always as intimidating or unattainable as it may initially appear! I have gained a lot of knowledge going through this process twice, and I'm always thrilled to help anyone in our community pursuing this path to motherhood. **We are all in this together!**



Surrogacy Resource:
<https://resolve.org>

FAMILY PLANNING:

Expanding the definition of family



Shelley's Story (ASD, heart block, heart failure)

Shelley has an Atrial Septal Defect, a third-degree heart block, a pacemaker, and heart failure.

I remember having a lot of conflicting feelings regarding having a baby. **I wanted to have a family more than anything** in this world. However, I always had a lot of fear surrounding pregnancy as a result of being born with a CHD. I was very afraid of passing on my heart conditions and possibly not living long enough to raise my children.

My story starts with the happiness of getting pregnant. This was an exciting time filled with dreams and hopes for the baby. Unfortunately, I lost the baby to a miscarriage. During an ultrasound, I was told my baby's heart stopped beating. This was extremely upsetting for me, having been born with a CHD myself, and it caused me a lot of sadness.

FAMILY PLANNING:

Expanding the definition of family



Shelley's Story ***(ASD, heart block, heart failure)***

I wanted to know why the baby's heart stopped beating, but **no one could give me an answer**. This led me to have a lot of guilt over the miscarriage. I blamed myself and worried that I passed down CHD to the baby.

We eventually started trying to get pregnant again, only to run into fertility issues. I **worried a lot about the fertility medicine being too strong for my heart** to handle.

After several failed fertility treatments, a new, stronger medicine was needed. This time, **the fertility specialist didn't feel comfortable** prescribing the medicine. He expressed concern and didn't seem comfortable having a patient with heart conditions.

At this point, we considered adoption, but instead **decided to stop trying to have a child**. Our marriage was very strained from all of the stress and disappointment of trying to have a baby.

FAMILY PLANNING:

Expanding the definition of family



Shelley's Story ***(ASD, heart block, heart failure)***

I didn't think it was possible to ever be happy being **childless**. Grief is a common thread among those of us who want a baby and are unable to fulfill this dream. I think the quote "grief is love with nowhere to go" explains it well.

I was eventually **able to find a home for my motherly love with my nieces and nephew!** They have brought so much joy, and so my story ends with happiness too!

I think it's **important to share that I wasn't under the care of an ACHD cardiologist.** This was a mistake. I had been under the care of my original cardiologist for a very long time, and it was difficult for me to transition to ACHD care. My ACHD cardiologist would have been able to bring an expert opinion regarding CHD and pregnancy, along with helping the fertility specialist feel comfortable having a congenital heart patient under his care.



FAMILY PLANNING

Family planning isn't just something for mothers with CHD to think about. If you are fathering a child, it is also important to communicate your CHD medical history to the obstetrician and to talk to your ACHD specialist.

The role genetics plays in the development of CHD is still in its early stages of research. Babies do have a higher risk of having a CHD if either parent, a sibling, or another close family member has a CHD.



Empowerment

Everyone's situation is unique, and family planning doesn't look the same for everybody.

The most important thing is to communicate with your doctors and to discuss family planning with your partner to decide what will be best for you.



AGING WITH CHD

A brief overview of CHD history.

The first successful surgical treatment for infants with CHD was the **Blalock-Taussig-Thomas (BTT) shunt**.

Developed in the 1940s and **widely adopted in the 1950s**, this procedure was designed to increase blood flow to the lungs and improve oxygen delivery to the body.

At the time, infants with low oxygen levels often appeared bluish, leading to the term “**blue babies**.” This procedure was a breakthrough, helping many infants survive conditions that were previously fatal.

This only happened 80 years ago. This means current patients with CHD are among the **first generation to live into adulthood**.



PEER EMPOWERMENT

Carol, Patient with Tetralogy of Fallot

“ I'm a 73-year-old TOF woman. Had a Blalock in 1953 and a "full correction" in 1963. I am still here today only because of my ACHD doctors. ”



AGING WITH CHD

Things to Note as You Age

As technology and medicine advance, adults with CHD are living longer. With that, some complications may arise over time. **It is important to continue seeing your ACHD doctor** for monitoring and health management.

Some important things to remember as you age with CHD:

- ◆ **Ongoing care with an ACHD specialist** is key. This will help you catch health problems earlier, monitor changes over time, and coordinate care with other specialists (as needed).
- ◆ Your care may extend beyond just your ACHD specialist. **CHD can affect other organs**, such as the liver, lungs, and kidneys. It is also important to maintain care with a Primary Care Provider (PCP).
- ◆ Gaps in care can increase health risks. **Continue to meet with your ACHD specialist** as directed.
- ◆ Everyone is at risk of **new health issues** as they age, whether you have a CHD or not.



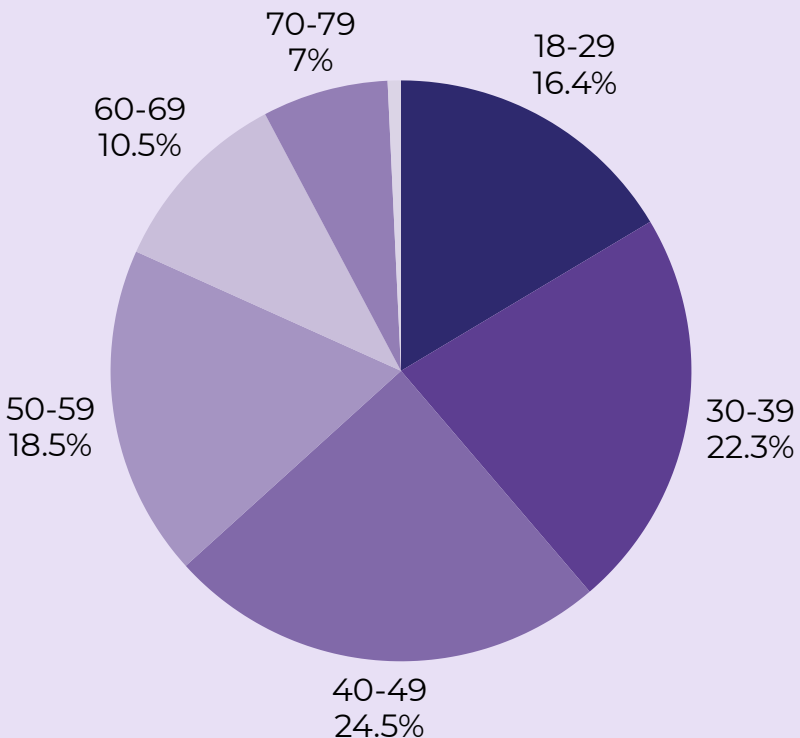
AGING WITH CHD

EmpowerMyCH Research Study: Age Demographic Snapshot

The EmpowerMyCH study currently has ~550 participants **between the ages of 19 and 86.***

Over **18%** of our study participants are **60 years old or older.***

Participant Ages
(in years)



*as of March 2026



AGING WITH CHD

Stay active!

As you age, you may be at risk for additional non-congenital heart conditions or other health challenges. Maintaining regular **exercise throughout your life** is a powerful way to protect your heart, improve overall health, and maintain energy and mobility.

Staying motivated can be tough, but strategies like exercising with a friend, joining a group class, or using fitness trackers or apps **can make it easier and more fun.**

If you're unsure where to begin, **EmpowerMyCH offers a comprehensive exercise guide** designed for people with CHD. It includes step-by-step instructions, inspiring stories from other patients who have successfully incorporated exercise into their routines, and practical tips to help you stay consistent and safe on your fitness journey.

Reminder: Always consult your ACHD specialist if you are unsure which exercises are right for you.

AGING WITH CHD:

Menopause



The medical field is still learning a lot about menopause and aging among women.

There is currently **no established CHD-specific practices** for managing menopause among those with CHD.

Below are some general options for managing menopause, but make sure to **discuss treatments with your ACHD specialist before starting anything new.** You may also see a gynecologist who specializes in complex conditions who can work with your ACHD cardiologist.

Medication Therapies:

- ◆ Hormone replacement therapy (HRT), including estrogen and alternative hormone options.
- ◆ Topical hormones (creams, patches).
- ◆ Non-hormonal medications for hot flashes and to prevent/treat osteoporosis.

Non-Medication Therapies:

- ◆ Relaxation activities (meditation, yoga, deep breathing exercises, massage).
- ◆ Avoid caffeine, alcohol, and spicy foods (recommended to minimize hot flashes)
- ◆ Pelvic floor physical therapy.
- ◆ Wear light layers, keep your environment cool using fans etc.