

Empower

Understand

Thrive



EMPOWER
MY CONGENITAL HEART



**Exercising with CHD:
Considerations &
How to
*Get Started!***



WHY IS EXERCISE IMPORTANT?

You may have been told as a kid to avoid exercise because of your CHD, but **studies now show that patients with CHD can benefit from exercising.**

Exercise is also important because patients with CHD may also **acquire additional heart disease** with age. **Exercise is essential to preventing this** and maintaining overall health.



CLINICIAN EMPOWERMENT

Katherine Salciccioli, MD,
ACHD Cardiologist

“Movement is medicine. Regular exercise is as important as any prescription in maintaining a healthy heart. Grab a friend, find an activity you enjoy, and get out there!”

If you are already exercising, you should continue.

Always check with your ACHD doctor about any restrictions on specific activities.



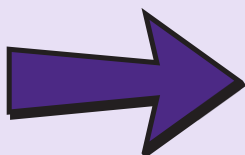
BRITTNEY'S STORY

I was diagnosed with a **double-inlet left ventricle** and had the **Fontan procedure** at an early age. Growing up, I was told to avoid physical activity. When it came to gym class, I was pulled out of certain activities, being advised that it wasn't good for my heart.

It wasn't until I became an adult that the messaging around exercise began to shift. **My cardiologist recommended that I begin incorporating movement** into my life. It was a strange adjustment. After years of caution, suddenly being told you should move more felt both liberating and terrifying.

I didn't really start until adulthood when I got the green light from my cardiologist. I had just **recovered from an ablation** and was terrified to push my heart rate at all. I was asked to join **Heart Club**, a clinical study at the University of Michigan focused on how exercise can improve Fontan health. I worked closely with an **exercise specialist and a doctor**, meeting with them weekly to talk through how I was feeling during my workouts. By the end of the 6-month program, I **could run a mile in under ten minutes**. Something I never thought would be possible for me!

**More of
Brittney's Story**





BRITTNEY'S STORY

Now, exercise is a regular part of my life. I am a mom of 2 and carry my "almost" 30-lb toddler up and down the stairs all day long without feeling exhausted. I am so grateful for the ability to do so.

To anyone with CHD who's hesitant to start moving, I want to say this: **You are stronger than you think.** While your exercise path might look different than others, that doesn't mean you can't do hard things. Start where you are. **You don't have to be perfect; you just have to begin.**



GENERAL EXERCISE GUIDELINES*

- ◆ At least **low-intensity activities** (walking, bowling, resistance training) are usually recommended.
- ◆ Your activity **recommendations may change** before and after treatment or repair(s) of your heart defect.
- ◆ If you have an **ICD/pacemaker**, consider protecting your device by avoiding repeated overhead motion, contact sports, and any consistent abrasive motion on the side of your device.
- ◆ If you take a **blood thinner**, consider avoiding body impact through contact sports or preventing internal injury.



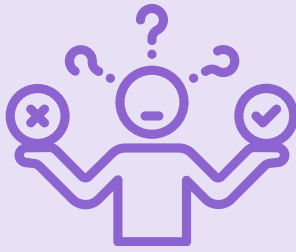
PEER EMPOWERMENT

Jennie, Patient with Tetralogy of Fallot with Pulmonary Atresia & MAPCAs

“It doesn't rule my life. Yes, I do have limitations, but respecting those limits and focusing on what I CAN do is so helpful.”

**Recommendations may differ based on your condition. Consult your ACHD doctor if you're unsure.*

KEY CONSIDERATIONS*



Fontan

- ◆ Resistance training (squats, lunges, leg presses, and calf raises) has been shown to improve exercise capacity, heart function, and quality of life in people with a Fontan procedure.
- ◆ Structured exercise programs, such as cardiac rehabilitation and home exercise prescriptions, can benefit most people with a Fontan.

Diseases of the Aorta

- ◆ Moderate aerobic exercise is safe and may be protective against progressive aortic enlargement.
- ◆ For strength training, choose weights you can lift for 12–15 reps, and avoid exercises that require holding one position (like a plank).
- ◆ Work on breathing through exercises instead of breath-holding to minimize stress on your aorta.

**Recommendations may differ based on your condition. Consult your ACHD doctor if you're unsure.*



CARDIAC REHAB

Cardiac rehabilitation can include exercise programs, as well as counseling, educational classes, dietary guidance, and condition management.

You can talk to your ACHD provider about getting a referral to cardiac rehab, though availability and insurance coverage can vary.

Can be a good option if you...

- ◆ Recently had a procedure or operation.
- ◆ Are struggling with exercise and need some help.
- ◆ Need support and guidance to manage your health and CHD condition better.



PEER EMPOWERMENT

Joe Valente, *Patient with Tetralogy of Fallot*

“ I did cardiac rehab 10 years after my last open-heart surgery. I had struggled to workout for those 10 years. Cardiac rehab helped me learn what was acceptable and feel successful again. ”

GETTING STARTED



**Start low & slow.
Build up fitness.**

- ◆ **Start off knowing what you can do**—everyone has to start somewhere.
- ◆ Even if you've avoided exercise for years, **today** is the day you can begin to make healthy changes in your life. Set a reachable goal for today.
- ◆ **Sometimes we have to start over** with exercising because of health setbacks or other changes, and that's okay!
- ◆ The simplest way to get started and improve your health is to **start moving**. It's free, easy, and can be done in place!
- ◆ If you're unsure of your exercise capacity, ask your cardiologist about a **cardiopulmonary exercise test** (CPET).



Community Event:

ACHA Walk for 1-in-100

www.achaheart.org/walk1in100



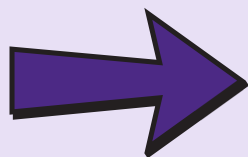
ANA CECILIA'S STORY

I was born in 1964 with **transposition of the great vessels, a single ventricle, and pulmonary stenosis**—a rare and complex combination of congenital heart defects. I was very limited to do any kind of exercise.

After my first open-heart surgery (**Fontan**) in 1989, I sensed that exercise could help me feel stronger and more alive. For many years, I walked about 30 minutes daily and practiced yoga 2-3x a week, simply **following what felt right**. But I didn't really know what was safe for someone like me.

That changed in 2021 when I met Dr. Valeria Duarte. For the first time, I felt safe—like I had someone who truly understood my heart condition and could guide me with knowledge and compassion. She **helped me understand my limits and possibilities, and gave me the confidence** to expand my movement safely.

**More of
Ana Cecilia's Story**





ANA CECILIA'S STORY

Since then, I've gradually **increased my daily walks** to an hour and a half and introduced **light weight training**. One of the most powerful affirmations came during a **cardiopulmonary exercise test (CPET)** on the treadmill—my results had significantly improved, even surprising my medical team.

To other CHD patients who are hesitant to start exercising: listen to your body and honor your inner voice. Trust that it will tell you when something is too much—or when you're ready to do more. Let go of fear. **Movement doesn't have to be extreme to be meaningful.** It can be a quiet, powerful act of trust and vitality.

EXERCISE TIPS

Remember, **every day is different** – some days you'll have more energy and be able to go further than on other days. That is ok! Take advantage of the good days!

Listen to your body, think positively and **assess your progress over a week or a month**, rather than a day.



Try to include exercise as part of your daily routine. **Everything counts** — like taking your dog for a stroll or walking around the mall.



Choose a physical activity **that you would enjoy** doing. Exercise can be fun!



PEER EMPOWERMENT

***Dominic**, Patient with
Tetralogy of Fallot*

“You can live a normal, productive life and stay in a positive frame of mind. Don't let fear and lack of confidence limit your physical abilities.”

HOW TO GET STARTED

Warm-Up!

Warm-ups are a great way to get your circulation going. A good warm-up should last about **5-10 minutes**.

May Include:

- ◆ Stretching
- ◆ Arm circles
- ◆ Hip circles
- ◆ Leg swings
- ◆ Jumping jacks



You may already exercise, or you may need to start from the beginning.

If you are just getting started, remember to **start low and slow**.

ACTIVITY EXAMPLES

Low-Intensity exercise can be beneficial for everyone.

Some examples include:

◆ Slow Walking

◆ Bowling

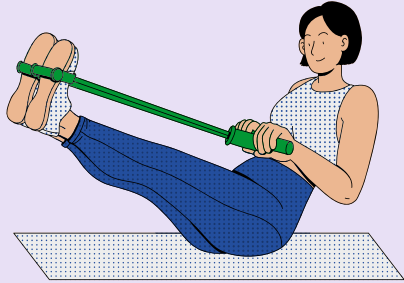
◆ Golf

◆ Resistance training (body weight exercise, resistance bands)

◆ Light Housework / Chores

◆ Restorative / Chair Yoga

◆ Tai Chi



EMPOWERMENT

Not all these activities will be a good fit for everyone. Find something that works for you currently and that you enjoy. It may feel challenging if you're just getting started or if you've had a setback and need to reset.

ACTIVITY EXAMPLES

Moderate-intensity exercise feels more challenging than low-intensity exercise. Some people may be able to work up to moderate intensity, but it may not be a good fit for everyone.

Some examples include:

◆ Brisk / Power Walking

◆ Water Aerobics

◆ Dancing

◆ Gardening

◆ Tennis

◆ Riding a Bike

◆ Pilates

◆ Yoga (introductory or intermediate)



EMPOWERMENT

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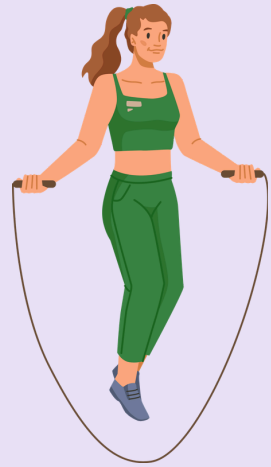
ACTIVITY EXAMPLES



High intensity exercise is typically very difficult and strenuous.

Some examples of high intensity exercise include:

- ◆ Hiking Uphill
- ◆ Running
- ◆ Jumping Rope
- ◆ Long distance / Speed Cycling
- ◆ Swimming Laps
- ◆ Powerlifting



EMPOWERMENT

Not all these activities will be a good fit for everyone. Find something that works for you currently and that you enjoy.

WHAT TO LOOK OUT FOR

If you notice any of the following while exercising, you should stop, rest, and hydrate.

- 1 Breathing too hard to be able to talk
- 2 Feeling dizzy or faint
- 3 Feeling extremely tired
- 4 Heartbeat feels strange or very fast
- 5 Unusually pale and clammy skin
- 6 Skin becomes more blue

**When in doubt,
listen to your
body!**



EMPOWERMENT

A common brief assessment is called the “Talk Test”: If you can't carry on a conversation without stopping for breath, you are exercising at a vigorous intensity.

For some, it may be hard to maintain conversation with “low intensity” activities, while others won't have difficulty until doing “high intensity activities”. If you are worried or unsure if you should be concerned about the symptoms you are experiencing, contact your doctor.

Know When to Call. Know When to Go.

Deciding whether you need to go to the emergency department (ED) or call your CHD cardiologist can be difficult. These are some general rules to keep in mind:



Urgent

If your symptoms are **sudden, severe, or worrisome, go to the nearest ED or call 911.** Provide the contact information for your CHD cardiologist. They can assist with your care and help determine if a transfer is needed.

Choose to be driven to your CHD center ED, bypassing the nearest ED if your symptoms are worsening from your baseline—but you are otherwise feeling stable.

Non-Urgent

If you decide to contact your **CHD clinic**, you might not get a response for a few days.

Unsure

If you are unsure about the urgency, call the CHD center and ask for the on-call CHD cardiologist. Most **CHD centers** have an **on-call CHD cardiologist available 24/7** to answer questions.



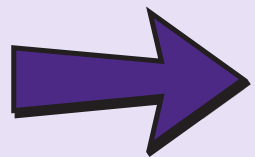
MELISSA'S STORY

When I was in the hospital at age 4 to repair my **Tetralogy of Fallot**, my dad bought me a Schwinn bicycle! They wouldn't let me ride it! As soon as I got home, I started learning to ride. I roller skated. I took swimming lessons.

As I grew, I rode bikes all around the neighborhood! I joined the swim team. I played baseball, basketball, and football with all the neighbors. I played high school volleyball and basketball. **I loved sports.** Although the doctors disqualified me from sports my junior year, I continued to run and lift weights.

In college, I **started cycling.** I rode all over San Diego and **climbed Mt. Soledad** many times. I had to give up cycling and **started running.** I have done over 10 half marathons and had a great time with my running community.

**More of
Melissa's Story**





MELISSA'S STORY

Exercise keeps me sane and healthy. If you do have to have an intervention, you will be much better off and recover faster if you go into it strong and healthy.

As **an athletic trainer and exercise physiologist**, I know the benefits of exercise go beyond the physical. It's not an option. **You MUST do it just like you must brush your teeth.**

Find what you love. Find your community. **The perfect exercise is the one you will do**, whether it is CrossFit, Zumba, or walking. If you try one thing and don't like it, try something else. Listen to your body and not influencers. If you are nervous for some reason about exercising, **ask your physician for a graded exercise test** so you know how far you can push yourself.

GETTING MOTIVATED!

It can be hard to feel motivated to exercise. Below are some things that may help.

Exercise with a buddy!

Exercising with a friend or loved one can make it easier and more fun.



Use technology for tracking, reminders, & habit-forming.

- ✓ Phone apps (*examples on next page*)
- ✓ Smart Watch
- ✓ FitBit
- ✓ Pedometer

Physical Activity Recommendation Form

You can use this form with your cardiologist to learn which types of exercise are safe for you. It can help you feel more confident getting started with being active.



Teen & Adult Tool Kit
bit.ly/exercise-toolkit

WHAT DO THE ICONS MEAN?




= This means the tool is a **mobile app** you can download and use on your smartphone or tablet.

How to Find an App

iPhone or iPad Users:

Open the App Store 

Android Users:

Open the Google Play Store 

Then, type the **app name** shown in this guide into the search bar and follow the instructions to download it.

What About Free vs Paid Apps?






= The app offers helpful tools in its **free version**—a good place to start.

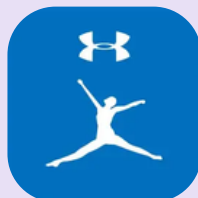





= Some features may require a **subscription** or **one-time payment** to unlock additional tools or reports.

GETTING MOTIVATED!



Apps for your Phone

MyFitnessPal   
Helps you track your progress towards your nutrition, water, fitness, and weight loss goals.



Caliber   
Combines resistance training, cardio, nutrition, and habit formation.



Streaks  
App for forming good habit and breaking bad ones.



HabitShare  
Social and collaborative habit tracker for building habits and tracking progress with friends.



Remember!

A little exercise is better than no exercise. You can work your way up.



Do whatever works for you!