

Finding out that you have a problem with one of your heart's valves can be worrying. You probably have lots of questions. You are not alone.

The American College of Cardiology has developed this and other tools based on input from people living with varying degrees of aortic stenosis and the types of information they found most useful. This resource is designed to help you understand aortic stenosis, how it may worsen over time and better know what to expect. *About My Aortic Stenosis* is a printable worksheet that you can use to write down information about your condition, track your symptoms, your treatment plan and questions.

Below are some common questions people who learn they have aortic stenosis have:

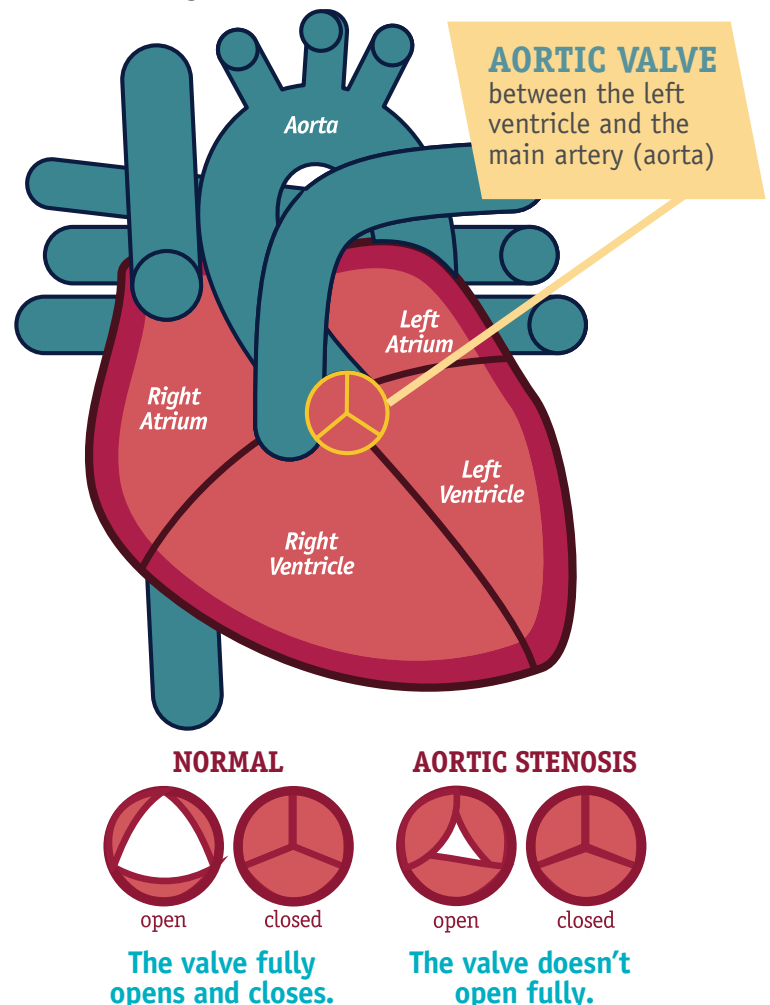
- ▶ What is aortic stenosis?
- ▶ What happens next now that I have been diagnosed with aortic stenosis?
- ▶ How will I know if my aortic stenosis is getting worse? What do I need to look for?
- ▶ When I have an echocardiogram, what is my doctor looking for?
- ▶ Has my aortic stenosis progressed?
- ▶ How do we decide which treatment is best?
- ▶ Are there any activities I should be avoiding?
- ▶ Is there anything I can do to keep my aortic stenosis from getting worse?
- ▶ What else can I do to protect my heart?

What is aortic stenosis?

Aortic stenosis happens when one of the valves in the heart—called the aortic valve—doesn't open fully. This narrowing (stenosis) makes it hard for blood to get out of the heart and to the rest of the

body. This can weaken the heart over time. When this happens, your body may not get the oxygen it needs. Fluid can also back up in the lungs.

Aortic stenosis can be mild, moderate or severe. It is a disease that progresses—meaning it gets worse over time. Your health care team will monitor your valve and how your heart is pumping. This is done through regular medical visits, echocardiograms and other tests.



I Have

Aortic Stenosis

Now What?

What happens next?

How your aortic stenosis will be followed and treated will depend on:

- ▶ How you are feeling
- ▶ What is seen on your echocardiogram and other tests
- ▶ Your goals for treatment
- ▶ Any other health conditions that you have, and your risk of heart disease



During early stages of the disease (mild or moderate), your doctor may decide to watch your condition. As it worsens, you will need to have your valve replaced. When your aortic stenosis requires intervention, your doctor will review all of the options available to you. If not, ask.

How will my heart team and I know if my aortic stenosis is getting worse? What do I need to look for?

Your symptoms and findings on the echocardiograms will help determine the severity of your aortic stenosis. Listen to your body, and make sure to tell your doctor about any new or worsening symptoms in between visits.

Common symptoms include:

- ▶ Chest pain, discomfort or tightness in the chest that often gets worse with exercise
- ▶ Feeling short of breath or overly tired
- ▶ Fainting spells or feeling dizzy or lightheaded
- ▶ Heart palpitations—when your heart skips a beat or flip flops in your chest
- ▶ Other signs:
 - Rapid weight gain
 - Swelling in your ankles/feet
 - Need to sleep sitting up/propped up with pillows
 - Dry cough

Pay attention to:

- ▶ When and how often you have these symptoms
- ▶ If your symptoms are getting worse
- ▶ Any activities that seem to trigger symptoms

It's also important for your health care team to know how aortic stenosis is affecting your life. Have you had a hard time:

- ▶ Sleeping
- ▶ Exercising (not being able to do as much or for as long)
- ▶ Walking short distances
- ▶ Working
- ▶ Doing routine tasks such as going to the grocery store, house or yard work or getting the mail
- ▶ In your relationships
- ▶ With your general outlook/mental and emotional well being
- ▶ Taking your medications

When I have an echocardiogram, what is my doctor looking for?

How you feel is only one part of the equation. Your doctor will also use a regular echocardiogram to get a closer look at your heart. This ultrasound test shows moving pictures of how your heart is working.

This test—also called an echo—allows your doctor to see and measure the:

- ▶ Size of the aortic valve
- ▶ Speed with which blood flows through the valve, also called “velocity”
- ▶ Pressure on either side of the valve, called the “gradient”
- ▶ The amount of blood your heart is able to squeeze out/flows through the valve (ejection fraction)

Ejection fraction (EF) is something you have probably heard your care team talk about. Your EF is one way to measure the amount of blood your heart is able to push out with each heart beat.



Pumping ability of the heart	Percent of blood in the ventricle that is pushed out of the heart with each beat
Normal	50-70%
Low	41-49%
Very low pumping, raising risk of serious problems	≤40%

Talk with your care team about your EF and what your other numbers mean.

What are my options for treatment?

It will depend on:

- ▶ How severe the narrowing of the valve is (measured by an echocardiogram)
- ▶ If you are having symptoms (Is your activity level today the same as it was six months ago? If not, why?)
- ▶ Does the benefit of getting a new valve outweigh any risk?

You and your doctor may:

- ▶ Watch and wait to see how your aortic stenosis progresses with repeat echocardiograms and other tests if you don't need surgery yet

- ▶ Decide it is severe enough that a heart valve replacement is warranted—either via open heart surgery or using a catheter inserted through an artery in the groin or the left chest

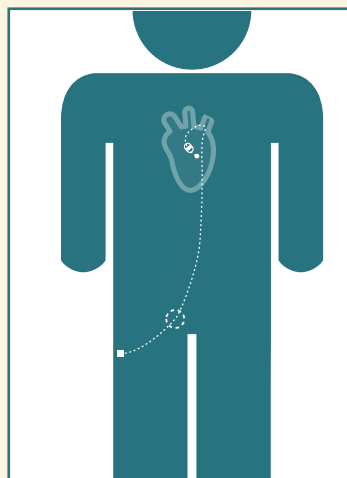
If your aortic stenosis is severe and you have symptoms—for example, chest pain, fainting, shortness of breath, and fatigue, or your heart function has worsened—aortic valve replacement is the recommended treatment.

You may also need to take certain medications to treat other heart disease risk factors and/or prevent clots or infections of the heart valve.

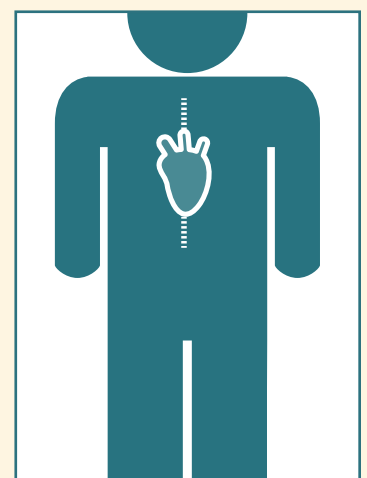
Leading a heart healthy lifestyle is important no matter how severe your aortic stenosis.

There are two ways to replace an aortic valve. The choice will depend on your condition and the risk of having open heart surgery. Your aortic valve can be replaced either by:

Transcatheter aortic valve replacement (TAVR) in which a new valve can be inserted using a small tube or catheter that is threaded through a vein to the heart.



Surgical aortic valve replacement (SAVR) in which a new valve is placed after opening the chest (rib cage) and removing the diseased valve.





Additional questions to ask:

Below are questions that other people with aortic stenosis say they wished they had asked.

- ▶ What caused the narrowing of my aortic valve?
 - ▶ Has my aortic stenosis progressed?
 - ▶ How do we decide which treatment is best (watch and wait or replacement)?
 - ▶ Are there any activities I should be avoiding? Can I exercise, and how much?
 - ▶ Is there anything I can do to keep my aortic stenosis from getting worse?
- ▶ What can I do to stay as healthy as I can?
 - ▶ At what point should I be seeing a valve specialist?
 - ▶ Am I a candidate for SAVR or TAVR? Why/why not?
 - ▶ How often should I come in for follow up visits? What about repeat echocardiograms?
 - ▶ Are there any resources to assist with out of pocket expenses for my echocardiograms and other costs related to my AS?



Helpful Resources

CardioSmart.org has a wealth of information and tools to help you in managing your condition. Be sure to check out our:

Patient Resource Guide:

Living Well with Heart Failure Workbook

Med Reminder App:

CardioSmart.org/Tools/Med-Reminder

While this resource describes how aortic stenosis typically progresses and what you might expect, remember that every case is different. Some people will be watched for a long time before a replacement is needed. For others, these procedures happen sooner because their condition quickly worsens. Be sure to talk openly with your health care team.

