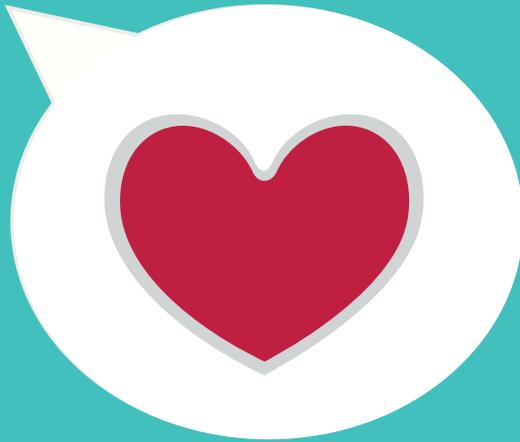


The GoToGuide for Valve Disease

A helpful resource for patients and caregivers

- Valve disease explained
- Know the symptoms
- Understanding treatment options
- Recent FDA approval for expanded use of TAVR
- What to expect during treatment





Let's Get Social

Stay up to date on heart health and connect with Mended Hearts any time. Find us at www.mendedhearts.org and on these sites:



facebook.com/mendedhearts

facebook.com/MendedLittleHeartsNationalOrganization



[@MendedHearts](https://twitter.com/MendedHearts)

[@MLH_CHD](https://twitter.com/MLH_CHD)



[Instagram.com/mendedlittleheartsnational](https://instagram.com/mendedlittleheartsnational)

The GoToGuide for **Valve Disease**

Valve Disease Explained **2**
Know the Symptoms **8**
Understanding Treatment Options **9**
Tools & Resources **18**



Mended Hearts gratefully
acknowledges the support of Edwards Lifesciences.



Valve Disease Explained

What is Valve Disease?

Heart disease is something we've all heard about, and for good reason: Right now, it's the leading cause of death in the United States, killing more than 600,000 Americans every year. (That's about one out of every four people.)

One common form of heart disease is valve disease, which occurs when one or more of your heart valves isn't working properly.

Your heart has four valves — the tricuspid, pulmonary, mitral and aortic. Each of these valves depends upon tissue flaps that open and close every time your heart beats. The flaps make sure blood flows in the right direction through your heart's four chambers and to the rest of your body.

However, sometimes certain things interfere with how well the heart valves function. Birth defects, age-related changes, infections or other conditions can cause one or more of your heart valves to not open fully or to let blood leak back into the heart chambers. This can make your heart work harder and affect its ability to pump blood.

The most common heart valve problems involve the aortic and mitral valves. Each year, according to the American College of Cardiology, about 5 million people are diagnosed with some sort of heart valve disease. There are four stages of heart valve disease, which range from being at risk for the condition to having severe heart valve disease with debilitating symptoms.

Stenosis vs. Regurgitation

When heart valves become too narrow for blood to pass through efficiently, this is called **stenosis**.

The narrowing is caused by things such as thickening, fibrosis and calcium deposits that build up on the valve. **Regurgitation** means the heart valves are leaking to some degree, and is also sometimes referred to as **insufficiency**.

Treatment options will vary based on the severity and progression of the disease, as well as on the patient's age and health.

Understanding Aortic Stenosis

Today, as Americans are living longer, incidences of heart valve disease are increasing. One of the most common and serious valve disease problems is aortic stenosis. It's the result of calcium deposits building up on the aortic heart valve, which causes it to narrow and reduce blood flow to the rest of the body.

Without treatment, it can become severe and life-threatening. Patients diagnosed with severe aortic stenosis have a survival rate as low as 50% two years after diagnosis, and 20% five years after diagnosis, unless they have aortic valve replacement.

That's why it's so important to understand heart valve disease, know the risk factors and be aware of its warning signs. As many as 50% of all cases go undiagnosed, so it's important to know the symptoms and, if you're experiencing them, discuss them with your doctor. Getting a second opinion is an option if you feel you're being misdiagnosed; remember that it's up to you to become your own health advocate.

Aortic Stenosis by the Numbers

Aortic stenosis causes the narrowing of the aortic heart valve and results in reduced blood flow to the rest of the body. It is more common in men than in women, and one of the biggest risk factors is old age. Here's a look at aortic stenosis by the numbers:

2.5 million

number of people over the age of 75 with aortic stenosis

12.4

percentage of population over the age of 75 with aortic stenosis

80

percentage of aortic stenosis patients who are male

80 million

projected population of adults over the age of 80 by the year 2050



Understanding Mitral Valve Regurgitation

Along with aortic stenosis, the most common form of heart valve disease is mitral valve regurgitation, which is also called mitral valve insufficiency. It occurs when the mitral valve doesn't close properly, and the blood flows backward into your heart. It can be caused by things such as mitral valve prolapse, damaged tissue cord, rheumatic fever, wear and tear on the heart, previous heart attacks, untreated high blood pressure and congenital heart defects.

While mild mitral valve regurgitation is not likely to cause other problems, severe mitral regurgitation can lead to complications that include heart failure, endocarditis, atrial fibrillation and pulmonary hypertension.

In most cases, if the condition is mild, no therapy or procedures will be required and the symptoms can be managed with medication. These medications may include blood thinners, diuretics and drugs that help control

uneven or abnormal heartbeats.

However, in cases where the regurgitation is severe enough, the patient might require surgery to repair or replace the faulty valve.

Other Forms of Heart Valve Disease

Although aortic stenosis and mitral valve regurgitation are the most common forms of heart valve disease, all four valves in the heart are susceptible to both stenosis and regurgitation. Other forms of heart valve disease are:

- **Mitral valve stenosis**, which is almost always the result of rheumatic fever. Rheumatic fever occurs when a childhood illness such as scarlet fever or strep throat is left untreated. It is far less prevalent in the U.S. today, thanks to the effective use of antibiotics that prevent infections. But it is still seen in countries with overcrowding and sanitation problems.
- **Mitral valve prolapse**, in which the two valve flaps of the mitral valve don't close smoothly or evenly. This allows blood to leak backward through the valve, causing a heart murmur. In most cases, it does not cause any long-term problems, but in some cases, treatment may be required. It may sometimes (but rarely) become a serious condition that causes abnormal heartbeats, called arrhythmias, that can eventually become life threatening.
- **Aortic valve regurgitation**, which is leakage of the aortic valve that allows

.....

In most cases, if mitral valve regurgitation is mild, no therapy or procedures will be required and the symptoms can be managed with medication.

.....

blood to flow in two directions (instead of just one) when the valve releases. This forces the heart to work harder to make up for the blood leaking back into the left ventricle. It's most often caused by high blood pressure, age or bacterial infection of the heart tissue. It can even be the result of untreated syphilis or injury.

- **Tricuspid valve stenosis**, which is the narrowing of the valve that restricts blood flow between the upper and lower parts of the right side of the heart. Most cases are caused either by infective endocarditis (an infection of the inner lining of your heart) or rheumatic fever.
- **Tricuspid valve regurgitation**, which allows leakage of blood backward into the right atrium. That leakage can cause the right atrium to enlarge and increase pressure in the nearby chambers and blood vessels. It is often caused by an enlarged lower heart chamber, but can also be influenced by diseases such as valve infection (infective endocarditis) or rheumatic fever, injury and carcinoid tumors. It was also associated with the use of the diet aid “Fen-Phen,” or phentermine and fenfluramine, which was pulled off the market in 1997.
- **Pulmonary valve stenosis**, which is caused by the narrowing of the pulmonary valve opening. It is most commonly caused by a congenital heart defect, although it can also be the result of rheumatic fever or carcinoid syndrome.

- **Pulmonary valve regurgitation**, which allows blood to flow back into the heart chamber before it gets to the lungs for oxygen. It is most commonly caused by pulmonary hypertension or a congenital heart defect, but can also be the result of infective endocarditis, carcinoid syndrome or rheumatic fever.

Drugs That Can Lead to Valve Diseases

There are several drugs — both prescription and recreational — that have been associated with the development of heart valve diseases. While these drugs are not a huge cause of heart valve disease, consider talking with your doctor about any of these drugs that you have taken or are currently taking.

AORTIC REGURGITATION

- Bromocriptine
- Cabergoline
- Dexfenfluramine
- Dexfenfluramine in combination with phentermine
- Ergotamine
- Fenfluramine
- Fenfluramine in combination with phentermine
- MDMA
- Methysergide
- Pergolide

MITRAL REGURGITATION

- Bromocriptine
- Cabergoline
- Dexfenfluramine
- Dexfenfluramine in combination with phentermine
- Ergotamine
- Fenfluramine
- Fenfluramine in combination with phentermine
- MDMA
- Methysergide
- Pergolide

TRICUSPID REGURGITATION

- Bromocriptine
- Cabergoline
- Ergotamine
- MDMA
- Methysergide
- Pergolide

MITRAL STENOSIS

- Ergotamine
- Methysergide

Know the Symptoms

Signs and Symptoms

The main sign of heart valve disease is an unusual heartbeat sound, which is called a heart murmur. It's something your doctor can hear with a stethoscope. But many people have heart murmurs without having heart valve disease, or they may have heart valve disease without any other signs or symptoms.

Other tests your doctor may use to determine if the murmur is abnormal could include a chest x-ray, electrocardiogram, echocardiogram or cardiac catheterization.

Heart valve disease often worsens over time, so in some cases, other signs and symptoms won't occur until many years after a heart murmur is first heard. People with heart valve disease often don't have any symptoms until they're middle-aged or older.

Other signs and symptoms include:

- Unusual fatigue/tiredness
- Shortness of breath or chest pain, especially when you exert yourself
- Shortness of breath when lying down
- Swelling in your ankles, feet, legs, abdomen and veins in the neck
- Chest pain that happens only when you exert yourself
- An irregular fast heart beat in the atria (atrial fibrillation or atrial flutter)

Some types of heart valve disease, such as aortic or mitral valve stenosis, can even cause dizziness or fainting.

.....
People with heart valve disease often don't have any symptoms until they're middle-aged or older.
.....

Understanding Treatment Options

Know Your Options

How your condition is treated will depend on the severity of your symptoms and your age. Whenever possible, doctors usually prefer to repair a valve and preserve the heart tissue. In some cases, however, the tissue may be too damaged and a replacement valve may be needed.

There are two types of valves: mechanical, which is man-made, and bioprosthetic, which is made from living tissue from an animal. Mechanical valves are known for their durability, but patients with a manufactured mechanical valve will typically need to be on blood-thinning medications for the rest of their lives.

In most cases, tricuspid and pulmonary valve disease will be repaired rather than replaced; in fact, replacement of either of these valves is fairly uncommon in adults.

The aortic and mitral valves are the two most commonly replaced valves in the heart.

Here's a closer look at some of the most common treatments for heart valve disease. Keep in mind that not all of these treatments are right for all patients or for every condition, so it's important to talk with your doctor about which options are best for you.

- **Balloon valvuloplasty.** This is a way to relieve stenosis, or narrowing of the arteries, and its symptoms, particularly in children and infants. It is less successful in adults, so it is rarely used unless they are too sick to

Are You Eligible for a Clinical Trial?

The U.S. National Institutes of Health offers an online registry that lists many ongoing clinical trials, including those for heart valve disease. Find out if you are eligible to participate in one of these studies by visiting [ClinicalTrials.gov](https://clinicaltrials.gov).

undergo surgery or need temporary relief while waiting for valve replacement. In this procedure, a physician inserts a catheter (a thin, flexible tube) into an artery in your groin or arm. The catheter has a tiny balloon attached to it. The doctor threads this balloon to the valve and inflates it. This stretches the opening to improve blood flow. Once the valve is opened, the balloon is deflated and removed.

- **Surgical Valve Replacement.** This requires open-heart surgery, during which the surgeon removes the diseased valve and replaces it with either a mechanical, man-made valve or a biological valve made from animal or human tissue.
- **Transcatheter Aortic Valve Replacement, or TAVR.** This relatively new procedure has quickly become one of the most common treatments for aortic stenosis. This procedure is less invasive than open-heart surgery and uses a catheter to put a new valve inside the diseased one. It's an ideal option for patients who are high-risk or too sick for open-heart surgery. In August 2016, the U.S. Food and Drug Administration approved a particular artificial valve — the SAPIEN 3, made by a cardiac device maker Edwards Lifesciences — for use in patients considered to be at an intermediate risk for complications from surgery. This means that more people will be eligible for the less-invasive TAVR procedure. There are many ongoing trials for TAVR in other populations. Trials are

now being conducted to test the safety and effectiveness of transcatheter mitral valve replacement.

- **Surgical valvuloplasty.** In rare cases, surgical repair may be a more effective option than balloon valvuloplasty, such as for infants born with an aortic valve in which the leaflets of the valve are fused together.

For people with severe aortic stenosis, the outlook is somewhat limited, as there is no way to treat or reverse symptoms other than aortic valve replacement. In those cases, the only two recommended treatment options are aortic valve replacement and TAVR.

Guidelines for Treatment

The American Heart Association and the American College of Cardiology updated their guidelines in 2014 to provide the latest information on the management of heart valve disease. In addition to recommending the TAVR procedure for patients with aortic stenosis who might find surgery too risky, their latest guidelines say:

- Patients with heart valve disease should have a team of health care providers working together to help manage their condition. This includes a cardiologist and a cardiac surgeon. Ideally, it would also include other experts who specialize in the management of patients with severe heart valve disease.
- Patients who need treatment for valve disease should consult with experts from a “Heart Valve Center of Excellence” that is

experienced in treating patients with their condition.

- Exercise testing is a useful way to evaluate patients with heart valve disease and should be used more widely to help assess the health of heart valve patients.

Lifestyle Changes

Diet and exercise are two things that are in your control, and even small changes in these areas can make a big difference. While lifestyle changes involving diet and exercise cannot reverse severe heart valve disease, such changes will improve your overall health and recovery. Also, commit to seeing your doctor regularly. This will let you know if your valve problem has gotten worse and/or if you need a more aggressive treatment plan. In some cases, a malfunctioning heart valve may never need surgical treatment, as long as you continue to monitor it.

While you cannot reverse severe valve disease, here are some important factors that play a key role in your overall heart health.

- **Smoking.** Not surprisingly, cigarette smoking is one of the biggest risk factors for heart valve disease, particularly for people under the age of 50. Smoking, on its own, is a known factor for increasing the risk of coronary heart disease. However, when combined with other factors, like poor diet or lack of exercise, it has an even greater effect. Smoking increases blood pressure, decreases exercise tolerance and increases the



tendency for blood to clot. It also increases the risk of recurrent coronary heart disease after bypass surgery. You should also limit exposure to second-hand smoke, which the Centers for Disease Control and Prevention says is responsible for about 34,000 cases of fatal heart disease each year.

- **Diet.** Learn which foods are good for you and which ones are doing harm. Dietary fats are a key place to start; getting rid of unhealthy fats, especially trans fats, and replacing them with healthy fats (such as avocado, coconut oil and nuts) is good for your heart and your waistline.

Other important dietary changes include restricting your intake of salt and sodium, which can lessen fluid retention and improve symptoms related to heart valve disease. Controlling portion sizes and eating more fresh fruits and vegetables also contribute to a heart-healthy lifestyle.



- **Exercise.** Exercise comes in many forms, and you'll want to talk with your doctor about which types of exercise are appropriate for your condition. Exercise helps keep your body strong and can reduce common risk factors for heart disease, such as high cholesterol and blood pressure. It is particularly useful for those with severe valve disease who don't recognize their symptoms.

All of these factors are more strongly linked to aortic stenosis than to other heart valve diseases, but improving them can help create overall good health. However, even if you improve your lifestyle habits, it's still important to be aware of your symptoms and monitor changes. If you experience an increase in fatigue, shortness of breath or any other symptoms, you should let your doctor know immediately.

Something to Talk About

In order for your doctor to help manage your condition, you'll want to provide the most thorough information possible. Before your initial visit with your doctor, check with family members to learn more about your family history. It's important to know your family's health history, including whether any close relatives have been diagnosed with cardiac disease and what kind of disease they have. To prepare for your appointment, you will also want to:

- Write down any symptoms you're experiencing, their severity and how long they have been occurring. Be as specific and accurate as possible.
- List all of your medical information. This should include your full health history, recent health problems and the names of all prescription and over-the-counter medications you're taking. Remember to include any herbal supplements as well.
- Ask a family member or friend to go with you to your appointment. There's a lot to remember, and this can be an emotional time. Take notes, or even record, what the doctor says so you can refer back to it after the appointment.

Before the appointment, write down any questions you want to ask your doctor, such as:

- What do you think is causing my symptoms?
- What tests do I need to get diagnosed?
- Should I see a cardiologist or heart team that is specially trained in treating my condition?

- How frequently will I need to have follow-up visits to monitor my condition?
- What are my treatment options?
- What is the outlook for someone with my condition?

In most cases, your health care will be managed by a team of specialists. You will begin by seeing your family doctor or cardiologist, who will refer you to a specialized heart valve team at a hospital or medical facility near you. Working with a “Heart Valve Center of Excellence,” as recommended by the American Heart Association and the American College of Cardiology, ensures that you receive the most qualified, experienced care available.

The health care team could include the following:

- Primary care physician
- Cardiologist
- Cardiovascular surgeon
- Interventional cardiologist
- Anesthesiologist
- Imaging specialist
- Valve clinic coordinators (for the treatment of aortic stenosis at TAVR Centers)
- Other specialized nurses and clinical staff

These experts each provide an area of knowledge and skill that, together, combine to provide you with the best care possible for your valve treatment.

What to Expect

Knowing what to expect from your procedure is important, too. It can help take away some



of the anxiety that naturally comes with any medical procedure.

Your heart team will create an after-care plan that you'll begin using immediately. They'll give you specific instructions to help make your recovery as quick and successful as possible. It may include a special diet, exercise and medication, depending upon the treatment. Always follow your doctor's directions, especially in cases where blood-thinning drugs are prescribed.

If you have questions, particularly when it comes to medication, make sure you reach out to your health team instead of trying to guess or taking chances.

Regular check-ups with your doctor are very important. Call your doctor whenever you have questions or concerns about your health. If you experience any unusual problems such as bleeding, pain, discomfort or changes in your overall health, be sure to contact your doctor.

Tools & Resources

Managing valve disease isn't something you have to do alone. Fortunately, there are many resources available today that can help you learn more about where you can go for information and support:

- **American Heart Association's Valvular Disease Education Center.** This site includes information on what to do after you've been diagnosed with valve disease, treatment options and resources.
www.heart.org/valves
- **CardioSmart.** The American College of Cardiology provides patient education and empowerment resources to help patients and their caregivers prevent, treat and manage all forms of cardiovascular disease.
www.CardioSmart.org
- **Heart Valve CareLine.** This is a great tool for patients, providers and caregivers who need help navigating the insurance world and accessing health care needs when dealing with the complication of a valvular condition. CareLine screens patient eligibility for a one-time, \$1,000 grant through the Heart Valve Financial Aid Fund.
www.heartvalve.pafcareline.org
- **HeartValveSurgery.com.** Created by a heart valve patient, this site is both an educational resource and an online support community for patients with heart valve disease.
www.heartvalvesurgery.com
- **NewHeartValve.com.** This is a comprehensive online resource for aortic valve stenosis



and treatment options, including transcatheter aortic valve replacement (TAVR), for patients, caregivers and their health care professionals. It includes information on how the procedure is performed, its risks and patient options. www.newheartvalve.com

- **Mended Hearts.** As the nation's largest peer-to-peer support network for heart patients and their families, Mended Hearts provides inspiration, information and support for heart disease patients and their families. Mended Hearts helps patients and caregivers from diagnosis through the journey of recovery with social, emotional and practical support. www.mendedhearts.org



Creating Your Support System

One important part of your journey is to have a reliable support system in place. Whether you're a patient or a caregiver, a support system is very important.

Patients need support to make you feel less alone. Joining a support group can help, as you'll meet survivors who will inspire you. And you'll be among others who are facing similar challenges. It's also good to have a strong support network of family and friends who can talk or listen when you're feeling frightened, angry or uncertain.

Support for Caregivers

Most people aren't prepared to be caregivers. It's something you learn as you go and, most of the time, you have more questions than answers. Caregivers face challenges every day; some are emotional, others are physical and some are financial.

If you are a caregiver on a daily basis, you will serve many important, but sometimes stressful, roles. You are a trusted partner and health care advocate for them. Making treatment decisions isn't always easy, but as their advocate, you can help them sort through the many questions, concerns and options they will face during their journey.

Find a caregiver's support group, which will give you a safe place to express your feelings. You'll also see that you're not alone and that many of your frustrations and feelings are shared by others. Taking time to do things you enjoy — whether it's a yoga class, watching a favorite TV show or taking a walk in the park — is also an important part ensuring that you're caring for yourself, too.

Sources

Dr. Robert Bonow
Professor of Cardiology at Northwestern University Feinberg School of Medicine

Columbia University Medical Center
(<http://columbiasurgery.org/heart/mitral-regurgitation>)

U.S. National Library of Medicine
(<https://medlineplus.gov/ency/article/000176.htm>)

WebMD

American College of Cardiology

CardioSmart

American Heart Association

Mended Hearts Medical Advisory Council

Wait! There's More

The Valve Disease GoToGuide is also available online at www.mendedhearts.org. The digital version includes the great information found in the print version, plus interactive content such as:

- Videos
- Audio clips
- Interactive quizzes to test your knowledge of heart valve disease
- Printable resources to help you manage your heart health

The Valve Disease GoToGuide is one in a series of helpful guides available from Mended Hearts and our generous sponsors. Be sure to check out these other educational guides on www.mendedhearts.org:

- Heart Attack
- AFib and Stroke
- HeartGuide Patient Resource
- Chronic Heart Failure
- Depression and Your Heart
- High Cholesterol and FH
- Medication Adherence
- Tips for Caregivers



Mended Hearts™