



Resources

[Applying for Social Security Disability Benefits with Chronic Heart Failure](#)

[Applying for PAN Foundation patient assistance funds for Medicare patients being treated for heart failure](#)

Patient Access Network (PAN) Foundation: www.panfoundation.org/heart-failure

MEDICARE: 1-800-MEDICARE (1-800-633-4227)

HealthCare.gov 1-800-318-2596

Medicaid.gov

DRUG ASSISTANCE: Medicare.gov

PHARMA COMPANIES: <http://www.drugs.com/pharmaceutical-companies.html>

OTHER SOCIETIES:

American College of Cardiology (ACC): (202) 375-6000

American Heart Association (AHA): (800) AHA-USA-1

Association for Heart Failure Nurses (AAHFN): (888) 45-AAHFN

American College of Clinical Pharmacy (ACCP): (913) 492-3311

The International Society for Heart and Lung Transplantation (ISHLT): (972) 490-9495

Heart Rhythm Society (HRS) 202-464-3400

Association of Black Cardiologists (ABC) 800-753-9222

American Medical Association (AMA) (800) 621-8335

Society for Academic Emergency Medicine (AEEM) (847) 813-9823 www.saem.org

Society of Hospital Medicine (SHM) (800) 843-3360

Association of Cardiologists of Indian Origin (AACIO) www.aacio.org (573)882-2296

Preventative Cardiology Nurses Association (PCNA) www.pcna.net (608) 250-2440

CMS NUMBERS FOR PROVIDER QUESTIONS: 877-486-2048

Important Facts About Heart Failure in the U.S.


- Heart failure is common, but often misunderstood, unrecognized or misdiagnosed.⁸ 5.7 million Americans have Heart Failure. Heart failure is the only major cardiovascular disorder on the rise.³
- Heart Failure has approximately 670,000 new cases diagnosed annually. In comparison, lung cancer affects² 106,000 Americans and approximately 235,000 new cases of breast cancer occur in the United States.⁷
- The number of deaths in in the United States from this condition has more than doubled since 1979, and is found to cause approximately 287,000 deaths a year.⁴
- Heart failure costs the nation an estimated \$32 billion each year.¹ inhealth care services, medications, and lost productivity.¹
- Less than 50 percent of patients are living five years after their initial diagnosis and less than 25 percent are alive at 10 years.⁵ Poor prognosis can be attributed to a limited understanding of how the heart weakens and insufficient private and government funding.

References

1. CDC.gov Heart Failure Fact Sheet
2. CDC.gov Surgeon General's Report
3. American College of Cardiology
4. Congestive Heart Failure Blog
5. Univ. of Maryland Medical Center
6. American Heart Association

7. National Cancer Institute

8. Iowa Heart Center



Taking Control of Heart Failure

Taking Control of Heart Failure

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This booklet was developed under the direction of the Heart Failure Society of America. The booklet is designed as an aid to patients/physicians and sets forth current information and opinions on the subject of heart failure. The information in this booklet does not dictate an exclusive regimen of treatments or procedures to be followed and should not be construed as excluding other acceptable methods of practice. Variations taking into account the needs of the individual patient, resources, and limitations unique to the institution or type of practice may be appropriate.

Important Information

Please write down important contact information in the space below. You may also want to share this information with family members and friends.

Health Care Provider Treating Me for Heart Failure:

Name _____

Address _____

City _____ State ____ ZIP _____

Phone _____

Fax _____

E-mail _____

Other Important Phone Numbers:

Ambulance, fire department, or emergency services: **911**

Pharmacy _____

Other health care providers:

What is Heart Failure?

Many people mistakenly believe that heart failure means that the heart has stopped or is about to stop. Heart failure simply means that the heart is not pumping blood through the body as well as it should. As the heart's pumping action weakens, blood backs up into the blood vessels around the lungs and causes seepage of fluid into the lungs. The fluid causes congestion and makes it hard to breathe. Sometimes the heart pumping is normal but there is an increase in pressure inside the heart. This can also cause problems with breathing. Many people with heart failure also have swollen legs and feet. That is why heart failure is sometimes called congestive heart failure.

Heart failure is a serious illness that can affect how long you live. You may have heard that some people may die sooner because of heart failure. But with proper medications in the right doses and careful management, you can live longer and feel better.

In most cases, heart failure can't be cured, but it can be brought under control with careful work on your part. Careful management means that you should:

- Take all of the medicines ordered by your doctor or nurse.
- Follow a low-sodium (salt) diet.
- Stop smoking.
- Remain physically active.
- Lose weight if you are overweight.
- Drink alcohol sparingly, if at all.

You should also check yourself every day for signs that your heart failure is getting worse. You should:

- Weigh yourself.
- Look for swelling. These things may seem hard to do. But your active input in the treatment plan is essential. This series of modules will give you many tips and ideas to make it easier for you to take control of your condition.



Causes of Heart Failure

Heart failure usually occurs when another problem makes the heart weak or stiff so it doesn't pump or fill normally. A common cause of heart failure is heart attack. The medical term your doctor may use for this cause of heart failure is ischemic cardiomyopathy.

Other non -“ischemic” causes of heart muscle dysfunction (cardiomyopathy) include high blood pressure, infection or inflammation of the heart muscle, lung disease, diabetes, and problems with the heart valves. Drinking too much alcohol for a long time can also cause heart failure.

Sometimes the exact cause of heart failure is not known. Idiopathic dilated cardiomyopathy is the medical term for this type of heart failure. Other dilated cardiomyopathies may be hereditary, which may be important for family members of a patient with dilated cardiomyopathy.

Ask your doctor for the cause(s) of your heart failure. There may be special things you can do to care for yourself, based on the specific reasons for your condition.



Taking Control of Heart Failure

Questions to Ask

The list of questions below can help you talk about heart failure with your doctor or nurse. The answers can help you understand heart failure better. Talking with your doctor or nurse will also help ensure that you are receiving the best possible care.

Always feel free to ask your doctor or nurse questions. You may want to have a family member or friend help you ask questions if you are not comfortable doing it alone.

Remember that an active partnership between you and your doctor and nurse makes for the best health care.

Do I have blockages in my coronary arteries?

Reason for asking this question: Coronary artery disease is the most common cause of heart failure. With this disease, blockages in the coronary arteries decrease or cut off the blood supply to portions of the heart muscle. Sometimes it is possible to open the blockages and restore the blood supply to the heart. This may improve heart function and reduce your symptoms. Knowing whether your heart failure is related to blocked coronary arteries can help your doctor plan the best treatment for you.

Is my blood pressure high? Is it under control?

Reason for asking these questions: High blood pressure is a major cause of heart failure. It can also make heart failure worse.

When someone has heart failure, it is wise to reduce the amount of strain on the heart in any way possible. Reducing blood pressure to normal levels is one important way to reduce strain on the heart. It is important for you to know your blood pressure and whether it is under control. That way you and your doctor can make sure it is managed well.

Are my heart valves damaged?

Reason for asking this question: Heart valve damage is another cause of heart failure. Sometimes, valve damage can be repaired so that heart failure improves. Therefore, it is important to know if your valves are damaged.

What is my heart function (ejection fraction)?

Reason for asking this question: Heart function is commonly assessed using a number called the ejection fraction. Some people mistakenly believe their ejection fraction indicates the amount of heart muscle that is still working. The ejection fraction refers to the percentage of blood that is pumped out of the heart each time it beats.

A heart does not pump all of the available blood out each time it beats. A normal heart pumps out or ejects only about 50-65% of the blood inside. If the heart is damaged, the ejection fraction frequently falls below 40%. This is called systolic heart failure. However, you can have a normal ejection fraction and still have heart failure. This may be related to a condition called diastolic heart failure.

An echocardiogram is the test most commonly used to evaluate heart function. The test will tell your doctor and you about your heart and heart valve function. Another test of heart function involves injecting a very small amount of radioactive material into your blood to produce images of your heart. This test is frequently called a radionuclide or MUGA scan.

It is important to know your heart function. Doing so helps guide your care. However, once your doctor has evaluated your heart function, it is not necessary to keep testing it.



Learn More

You can learn more about how to take control of your heart failure by reading the other modules in this series. You can get copies of these modules from your health care provider. Or you can visit the Heart Failure Society of America website at www.hfsa.org.

The topics covered in the other modules include:

- *How to Follow a Low-Sodium Diet*
- *Heart Failure Medicines*
- *Self-Care: Following Your Treatment Plan and Dealing with Your Symptoms*
- *Exercise and Activity*
- *Managing Feelings About Heart Failure*
- *Tips for Family and Friends*
- *Lifestyle Changes: Managing Other Chronic Conditions*
- *Advance Care Planning*
- *Heart Rhythm Problems*
- *How to Evaluate Claims of New Heart Failure Treatments and Cures*

These modules are not intended to replace regular medical care. You should see your health care provider regularly. The information in these modules can help you work better with your health care provider.

Notes:



About the Heart Failure Society of America, Inc.

In the spring of 1994, a small group of academic cardiologists gathered in New York to discuss the formation of a society that would focus on heart failure. This group had long recognized that the disease was on the rise; yet there was no venue for researchers, trainees, and clinicians to gather to discuss new treatments, research results, and the rise in health care costs associated with heart failure. A society dedicated to heart failure would bring together health care professionals, including researchers, physicians, nurses, and other allied health care professionals, to learn more about the mechanisms of the disease, how best to treat patients, play a role in reducing health care costs, etc. The meeting led to the incorporation of the Heart Failure Society of America, Inc.

The Heart Failure Society of America, Inc. (HFSA) represents the first organized effort by heart failure experts from the Americas to provide a forum for all those interested in heart function, heart failure, and congestive heart failure (CHF) research and patient care.



Quick Heart Failure Facts

Q: What is heart failure?

A: Heart failure is a progressive condition in which the heart's muscle becomes weakened after it is injured from something like a heart attack or high blood pressure and gradually loses its ability to pump enough blood to supply the body's needs. Many people don't even know they have it because its symptoms are often mistaken for signs of getting older. Heart failure does not develop overnight – it's a progressive disease that starts slowly and gets worse over time.

Q: How common is heart failure?

A: Heart failure is common, but unrecognized and often misdiagnosed. It affects nearly **5 million Americans**. Heart failure is the only major cardiovascular disorder on the rise. An estimated 400,000 to 700,000 new cases of heart failure are diagnosed each year and the number of deaths in the United States from this condition has more than doubled since 1979, averaging 250,000 annually.

Q: How much money per year is spent on heart failure research?

A: The 5 million Americans suffering from heart failure received \$28.7 million in research dollars. In comparison, lung cancer research, which affects 390,000 Americans, received \$132 million.

Q: What is the prognosis for a patient with heart failure?

A: Less than 50 percent of patients are living five years after their initial diagnosis and less than 25 percent are alive at 10 years. Poor prognosis can be attributed to a limited understanding of how the heart weakens and insufficient private and government funding.

Q: What causes heart failure?

A: Although heart failure may strike at any age, it is more common in people over the age of 65. Heart failure risks include:

- High blood pressure
- Prior heart attack
- History of heart murmurs
- Enlarged heart
- Diabetes
- Family history of an enlarged heart

Q: What are the symptoms of heart failure?

A: The symptoms of heart failure may be subtle and are often mistaken for normal signs of aging. Common symptoms of heart failure are:

- Shortness of breath, which can happen even during mild activity
- Difficulty breathing when lying down
- Weight gain with the swelling in the legs and ankles from fluid retention
- General fatigue and weakness

Q: How is heart failure diagnosed?

A: Doctors often order a number of tests when exploring a possible diagnosis of heart failure. The most important of these test is the echocardiogram, or “echo”, which tells a person what their ejection fraction (EF) is. The ejection fraction is a measurement of how well the heart is pumping. People with a healthy heart have an EF of about 60 percent, while people with heart failure have an EF of 40 percent or less.

With early diagnosis and newer treatments, people with heart failure are able to continue enjoying their everyday activities and have a more normal life expectancy. Experts now recommend a three to four drug combination to treat heart failure, which include digoxin to help the heart pump better and improve blood circulation and diuretics, sometimes called water pills, to help remove extra fluid in the body and reduce swelling in the legs and ankles. Two newer classes of medications, ACE inhibitors and beta blockers have been shown to slow disease progression and work by blocking certain stress hormones in the body that are believed to be responsible for the progression of heart failure.