



Living with Heart Failure



Working together to improve the diagnosis, treatment
and quality of life for all those affected by arrhythmias

www.heartrhythmalliance.org

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Glossary

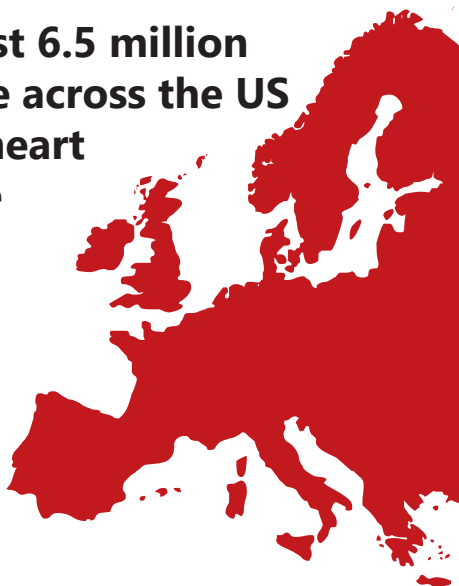
Echocardiogram A scan or sonogram of the heart that evaluates the structure of the valves and heart chambers

Ejection Fraction A measurement, expressed as a percentage, of how much blood the left ventricle (the main pumping chamber of the heart) pumps out with each beat

Electrocardiogram (EKG) A simple test that records the heart's rhythm and rate

Heart Failure The medical term used to describe the situation where the heart is unable to pump blood around the body as efficiently as it should

At least 6.5 million people across the US have heart failure



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What is heart failure?

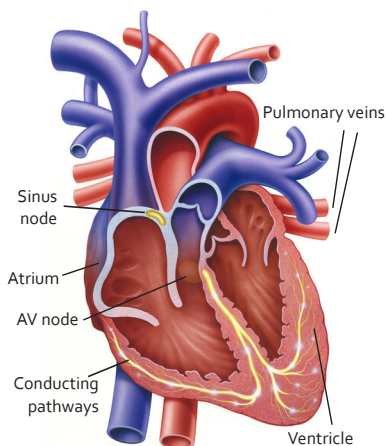
The heart's role is to pump blood around the body, ensuring that oxygen, blood and nutrients get to all of the muscles and organs. Heart failure is a condition in which your heart does not pump blood as efficiently around your body as it should, which makes it difficult for your body to get as much oxygen and blood as it needs. When the organs do not get enough oxygen to work effectively, this can then cause a number of symptoms, particularly after being active.

Although the term heart failure can sound scary, it does not mean that your heart is just going to stop working. Although heart failure is a serious medical condition, it only means that the heart is not working properly, and needs some support to help it work better.

Doctors often refer to two main types of heart failure. The two types are based on the ejection fraction, which is the proportion of blood pumped out of the main pumping chamber of the heart (the left ventricle) during a heartbeat.

The most common type of heart failure is that with a low ejection fraction (less than 50%). Increasingly common is the other main type of heart failure, where the ejection fraction is still normal (between 50% and 75%). Your doctor will tell you what type of heart failure you have, and what the treatment options are.

The heart and normal conduction



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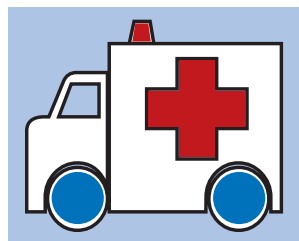
Another classification of heart failure, is right heart failure and left heart failure. Right heart failure is when blood may back up on the right side of the heart, causing swelling in the legs, abdomen and other organs. Left heart failure is when blood may back up from the left side of the heart to the lungs which causes congestion in the lungs and breathlessness.

Symptoms of heart failure

One of the most common symptoms of heart failure is breathlessness, which worsens with physical activity or exercise. Congestion, or fluid, can build up on the lungs which can make it difficult to breathe. This can happen when you are exercising or have been active, or in more severe cases can also happen at rest. It can also happen at night when lying down and may affect sleep. This build-up of fluid can also cause swollen ankles, legs or abdomen, as the heart is not pumping effectively enough to remove this fluid. A persistent cough may also develop, due to the excess fluid sitting in the lungs.

Tiredness caused by the heart's reduced function is very common, as less oxygen and nutrients for energy are being delivered around the body. This in turn can make everyday activities more difficult and exhausting, particularly exercise.

Other symptoms can include palpitation, a rapid or irregular heartbeat, weakness, dizziness or fainting, rapid weight gain from fluid retention or decreased alertness.



Heart failure is one of the leading causes of hospitalizations (about 900,000) in the U.S. annually. That's approximately 2 every minute.

Diagnosing heart failure

Heart failure is usually diagnosed by a doctor assessing symptoms and medical history, and various medical tests. You may be referred to a cardiologist. Tests will include checking your heart rate and rhythm, taking your blood pressure, checking the fluid in parts of the body including your legs, ankles, and tummy. Further testing may include an electrocardiogram (EKG), blood tests, an echocardiogram, and a chest radiography (an x-ray).



An EKG is a simple, non-invasive and quick test that looks at the electrical activity in your heart. This 12 lead EKG will show whether the heart is beating fast or slow and also shows if the rhythm is regular or not. Because there are electrodes on the chest and legs, this gives different views of the electrical activity of the heart and allows a specialist to understand if there is anything unusual. It can also tell your doctor if you've had a heart attack and whether part of your heart is thickened.

Blood tests will show your blood cell count, and kidney function, which if not normal, can also be a sign of heart failure. A special blood test (natriuretic peptide or NP), is particularly good at telling your doctor whether you may or may not have heart failure. Your GP should be able to organize this for you if they think you have developed heart failure.

An echocardiogram is an ultrasound scan which looks at the structure of the heart, whether there is any damage, and how well it is working. If you have symptoms and your NP blood test is high, your GP should organize this for you.

A chest x-ray will show any signs of congestion or fluid on the lungs. It will also show the size and structure of the heart. An MRI scan can also show the structure of the heart.

What are the causes of heart failure?

There are lots of conditions that can cause or contribute towards heart failure by changing the structure or functioning of the heart. The main causes of heart failure are:

- High blood pressure
- Coronary heart disease, including previous heart attack
- Cardiomyopathy (which may be genetic and run in your family)
- Damage to the heart valves
- Various heart rhythm problems
- Congenital heart disease (heart disease you are born with)
- Myocarditis (inflammation of the heart muscle, usually caused by a virus)
- Some drugs used in cancer treatment
- Excessive alcohol consumption

What treatments are there for heart failure?

As such, there is not usually a 'cure' for heart failure. There are however many treatment options that control symptoms, ease discomfort, and allow people with heart failure to lead a happy and healthy life. Lifestyle changes, medications, medical devices and surgery, are different treatment options for people with heart failure. The options will be discussed with you, and will depend greatly on your symptoms, the severity of your condition and what is causing your heart failure.

Medications:

There are many different types of medications for people with heart failure, all aiming to reduce symptoms, control the condition, and allow you to live a more comfortable life. Your doctor, heart failure nurse, or pharmacist will be able to discuss the medications appropriate for you. Some of the medications that may be used in your treatment for heart failure are described below.

Diuretics

Often known as water tablets, diuretics aim to reduce water retention in the body, by encouraging the kidneys to produce more urine. The water retention causes swelling of the legs, ankles and abdomen, and fluid build-up on the lungs, and many people feel they are able to breathe better once they start taking this medication.

ACE inhibitors

Angiotensin-converting enzyme (ACE) inhibitors work by widening the blood vessels, making it easier for your heart to pump blood around your body, and taking strain off the heart. ACE inhibitors are also used for hypertension (high blood pressure), so are also helpful to lower blood pressure.

Angiotensin II Receptor Blockers (ARBs)

ARBs work in a similar way to ACE inhibitors and enlarges blood vessels while also lowering blood pressure. ARBs are often prescribed for people who cannot take ACE inhibitors.

Sacubitril valsartan

For some patients, an ACE inhibitor or ARB will be replaced with a more modern drug, sacubitril valsartan, which also helps take the strain of your heart and helps the body cope better with the pump problem.

Beta blockers

Beta blockers work by slowing down the heart rate, lowering blood pressure, and helping to control arrhythmias. They can help to improve symptoms and gradually over time may improve the heart's pumping ability. Ivabradine may be used in place of beta blockers for those that are unable to take them, or may be added to your beta blocker to slow your heart rate more.

Mineralocorticoid receptor antagonists (spironolactone or eplerenone)

One of these drugs is usually used in addition to an ACE inhibitor and beta-blocker for people with heart failure and a low ejection fraction. It helps to stabilize the heart failure.

SGLT2 inhibitors (dapagliflozin, or empagliflozin)

One of these drugs is recommended for people with heart failure and low ejection fraction. Originally developed to help control diabetes, these drugs are now known to help control the heart failure syndrome better.

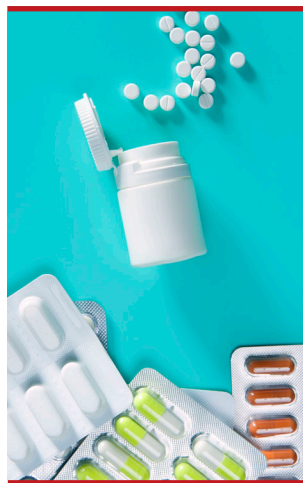
Digoxin

Digoxin is a medication which helps to slow down the heart rate and strengthen the heartbeat. Digoxin is typically used when ACE inhibitors, ARBs, diuretics and beta blockers don't work effectively, or as a first-line treatment for people with heart failure and atrial fibrillation.

Anticoagulants

If you have heart failure and atrial fibrillation (AF), it is more likely for you to get blood clots, and therefore be at risk of an AF-related stroke. If this is the case, an anticoagulant will be prescribed for you. Anticoagulants work to reduce the risk of blood clots forming in the body.

If you would like more information about anticoagulants or AF, please contact the AF Association on 843-415-1886 or email info-us@afa.org.uk



Devices:

Pacemakers

There are a number of different types of pacemakers. Pacemakers electrically stimulate the heart, making sure your heartbeat never goes too slowly. This may be particularly beneficial if fainting is one of your symptoms. Implanting a pacemaker will help you to maintain a suitable heart rate and rhythm.

Cardiac Resynchronization Therapy (CRT) Devices

Cardiac resynchronization therapy (CRT) devices are used to help treat heart failure, and can either be a permanent pacemaker alone (CRT-P), or combined with an implantable cardiac defibrillator (ICD) as CRT-D. These devices work by making the lower heart chambers (ventricles) pump and contract at the same time and improve the overall function of the heart so that you hopefully feel less breathless and have more energy. If combined with an ICD they can also help treat any dangerous fast heart rhythms that may occur (please see more details below).

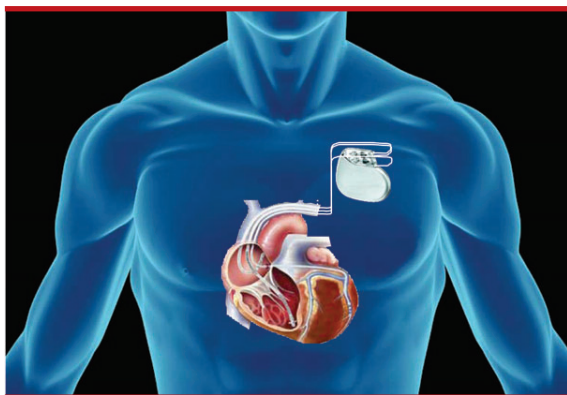
CRT Pacemakers (CRT-P)

These devices work in a similar way to traditional pacemakers. They help the heart to beat in a regular rhythm and are especially useful when the heart's natural pacemaker stops working properly. An implanted pacemaker sends out electrical signals which make the heartbeat in a regular fashion. A traditional pacemaker has either one or two leads which are put into the right side of your heart. One lead will be put into the lower right chamber (right ventricle) and a second lead may be put in the right upper chamber (right atrium). However, if you have heart failure you may need the more advanced type of pacemaker, the CRT-P.

The main difference with a CRT pacemaker, is that an additional lead is placed on the left side of the heart and electrical signals can make the left ventricle beat at the same time as the right. This can restore the heart's coordination and make the heart pump more efficiently. In two out of three people implanted with a CRT pacemaker, symptoms of breathlessness improve and they have more energy, but some people feel no benefit.

CRT ICDs

People who have had a fast abnormal heart rhythm, or who are at risk of developing one in the future, and who also need a CRT-pacemaker, may be suitable for a combined device. This is called a CRT-defibrillator, or CRT ICD, and works in much the same way as the standard ICD (see below).



It also has the advantage of often improving symptoms of heart failure, in the same way as the CRT-pacemaker. Your cardiologist will advise you as to what is best for you.

Implantable Cardioverter Defibrillator (ICD)

Sometimes, heart failure can lead to a rapid or irregular heart rhythm (arrhythmia), the result of which may be dangerous. An ICD will recognize and monitor your heart rhythm and will deliver electrical therapy or a shock to get your heart back into normal sinus rhythm if it is required.



1 in 5 of us will develop heart failure at some time in our lives

*National Heart Failure Audit
April 2015-March 2016

Surgery

Surgery may sometimes be needed to treat heart failure to improve the symptoms of the condition if medications and lifestyle changes on their own are not effective enough or if there is an abnormality of the heart valves or the blood supply to the heart muscle. These are some of the various surgery options that are available for heart failure.

Angioplasty or bypass surgery

These procedures may be used when heart failure is caused by coronary heart disease (furring up of the arteries supplying blood to the heart muscle). A coronary angioplasty is used when the arteries need to be widened, so a small balloon is inserted to stretch and widen the artery. Usually a metal scaffold (a stent) is placed to keep the artery open. Bypass surgery is a surgical operation that uses blood vessels from another part of the body to "bypass" the severe narrowing's in the coronary arteries.

Heart valve surgery

Heart valve surgery is used when the valves of the heart are damaged or diseased, causing heart failure. The valves can be repaired or replaced, which may help to improve symptoms.

Heart transplant

A heart transplant may be necessary if your condition is extremely severe, and medication and medical devices are not working for you. During this procedure, the failing heart is removed, and replaced with a healthy heart from a donor.

Left Ventricular Assist Devices (LVADs)

These mechanical devices are used to help the heart pump blood out of the left ventricle when it is not doing it properly itself. The device is usually used to support the heart while waiting for a transplant.

Classes of heart failure

There are several different classes of heart failure which are used to describe the severity of the condition. As a guide, here is the classification used by doctors:

- Class 1- There are no limitations to performing activities, and there tends to be no symptoms (on treatment).
- Class 2- Activities may be mildly affected, and more strenuous daily activities may cause palpitations or breathlessness.
- Class 3- There is a noticeable limitation to performing activities, and usually the person will only be comfortable when at rest.
- Class 4- Activities are extremely limited and doing any activity will cause symptoms. The person has symptoms such as breathlessness even at rest.

Living with heart failure

A diagnosis can be very frightening and worrying for most people. It can bring about an overwhelming feeling of uncertainty, and it is often hard to know what to do for the best. Not only is the diagnosis of heart failure itself very concerning, but the symptoms of the condition can make it hard for people to live a normal and happy life.

There are small changes that you can make to the way that you perform everyday tasks, that may make it easier to live with your condition. One thing you can do, is to try and do any jobs or activities in smaller tasks or sections, which will help you to conserve your energy.

A feeling of anxiety or sadness about your condition and symptoms is a normal and common reaction. It is understandable to feel down about the limitations that your symptoms may be having on your life, it can be difficult to come to grips with the uncertain nature of your condition.

It is important to find ways to manage the stress and anxiety that you may be feeling, as this can have a negative impact on your heart failure. It can be very helpful to talk to friends and family about your feelings and condition, you may find it helpful to speak to your doctor or heart failure nurse.

Cognitive Behavioral Therapy (CBT) is a structured talking therapy that can help an individual to accept and adjust as best as they can to their condition. It is not a cure but can help with quality of life. Therapy can be particularly useful in helping you to cope better with some of the symptoms and can help if mood has become low or 'blue'. If you feel that CBT may be helpful to you, you may get a referral by speaking to your GP

Learning about your condition can also be very helpful and powerful in managing your condition. Knowing all of your treatment options, how to best manage heart failure and any lifestyle changes may help you to feel more in control of your condition.



Lifestyle

After the diagnosis of heart failure, it will almost always be necessary to make small changes to your lifestyle. Of course, it is extremely important to live as healthy a lifestyle as possible, and eat a nutritious and balanced, balanced diet to maintain a healthy weight. Not only will this help with your overall health and fitness but being overweight can also exacerbate your symptoms due to added pressure on your heart and lungs.



Cutting down on your salt intake is another important part of your diet, as salt can increase water retention and raise your blood pressure. It is a good idea to speak with your specialist or heart failure nurse about guidelines for salt intake, and guidance on diet. Salt restriction may not be needed for everyone.

Due to water retention being a symptom of heart failure, it may be a good idea to monitor how much fluid you drink in a day. For specific guidelines, check with your specialist or heart failure nurse.

Drinking alcohol can increase blood pressure and worsen the symptoms of heart failure, so minimizing your alcohol intake or cutting out alcohol completely is a good idea. Caffeine can also raise your heart rate as well as increase blood pressure and switching to decaf options may be beneficial for those with heart failure.

It may take you longer to perform daily activities than it did before, but listen to your body, and take more time to do things. Rest if you need to, especially if you are feeling unwell or tired. Take time between tasks, and if you have an especially busy day ahead, make sure that you are well rested. Although it is sometimes more difficult with heart failure, it is still important to try and take regular exercise. This will improve symptoms of your condition and help to maintain overall health and fitness.

Notes

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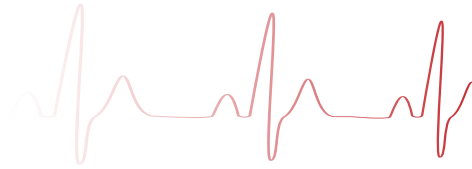
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This booklet has been written to support those diagnosed with an arrhythmia and their carers, who struggle to find information on this condition. Without donations and fundraising, we would not be able to provide support through our award-winning resources and helpline.



Working together to
improve the diagnosis,
treatment and quality
of life for all those
affected by arrhythmias



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"When you hear the words "heart failure" you think that your life is over - which is just not true"

Audrey

Please remember that this publication provides general information. You should always discuss and seek advice from your healthcare professional what is most appropriate for you.

Acknowledgments: Arrhythmia Alliance would like to thank all those who helped in the development and review of this publication. Particular thanks are given to Professor Martin Cowie, Dr Charlotte D'Souza and Francesca Lobban.

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