

A close-up photograph of a middle-aged couple smiling warmly at the camera. The woman, on the left, has long, wavy brown hair and is wearing a dark top. The man, on the right, has short, graying hair and is wearing a light blue shirt. They are both smiling broadly, showing their teeth. The woman's hand is resting on the man's shoulder, and she is wearing a ring on her finger. The background is softly blurred, suggesting an outdoor setting with greenery.

Patient Education  
[intermountainhealthcare.org/heartfailure](http://intermountainhealthcare.org/heartfailure)

# Living with Heart Failure

 Intermountain®  
Healthcare





### **A NEW ROLE TO PLAY**

Having heart failure doesn't mean that you can't live a full and rewarding life. But it does mean that you need to play an active role in taking care of yourself. This guide will help.



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## INTRODUCTION

If you've been diagnosed with heart failure, you're not alone. More than 6 million people in the U.S. have it. About 550,000 new cases are diagnosed every year. While heart failure is more common as a person ages, it also can occur in younger people. It is the leading cause of hospitalization in people over age 65.

Heart failure is a serious condition. But, there is a lot you can do to manage your condition and lead a satisfying and productive life.

This guide will help you understand your condition and what you can expect from your medical treatment. It will also help you see what you can do to improve your health now and in the future.



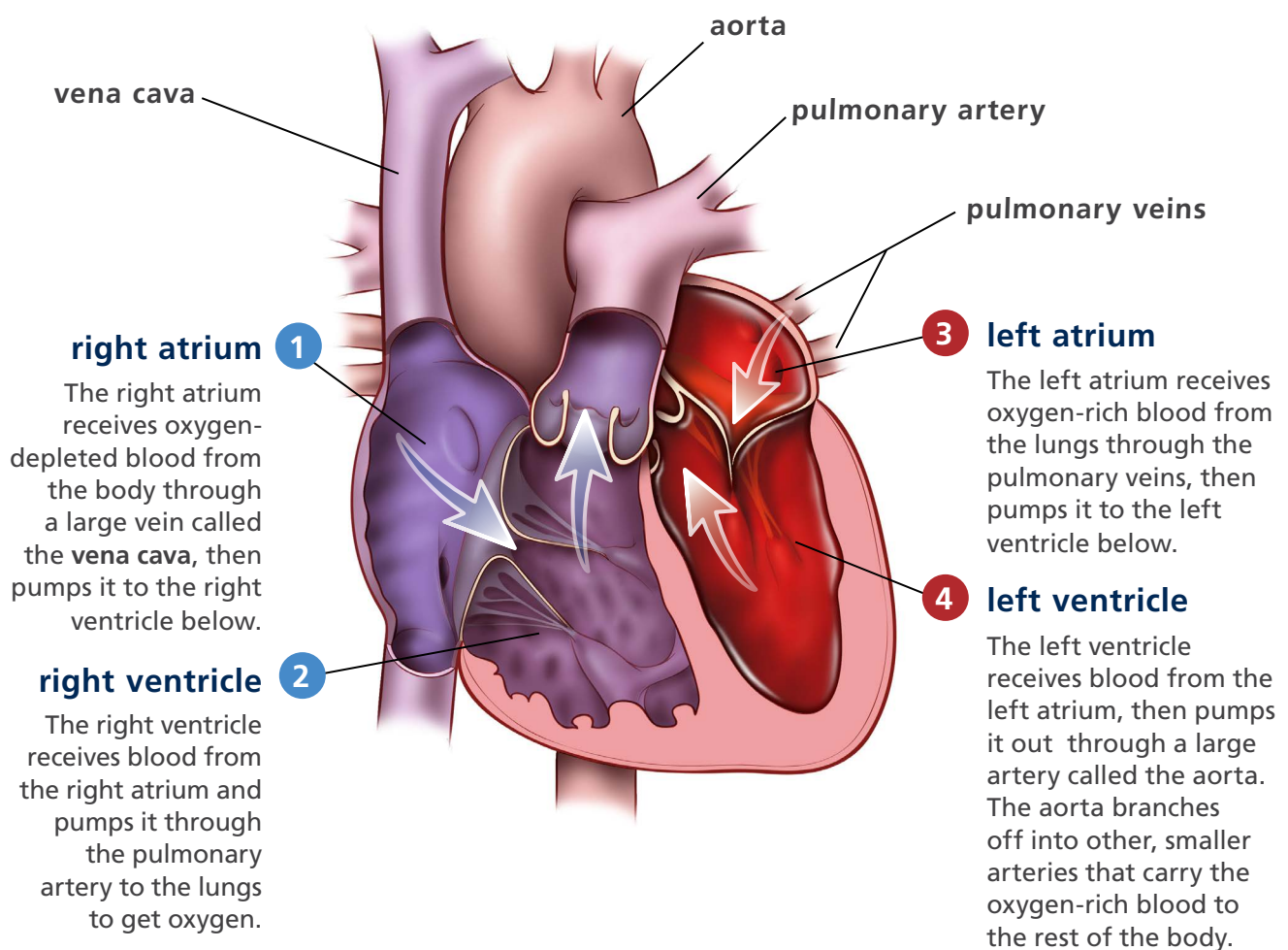
# Understanding Heart Failure

Your treatment plan will make more sense to you if you have a good understanding of what happens when you have heart failure. But first, it helps to know how a healthy heart works.

## How does a healthy heart work?

Your heart's job is to pump blood that is rich in oxygen and nutrients to all parts of your body. The picture below shows how this happens.

### The 4 pumping chambers of the heart



### YOUR HARD-WORKING HEART

Your heart is a hard-working muscle. On average, it beats 60 to 100 times each minute, every day of your life. Each beat pumps blood to all parts of your body. By the time you're 70 years old, your heart will have pumped almost 50 million gallons of blood. That is a lot of work for an organ about the size of your fist!



## What happens with heart failure?

When you have heart failure or heart muscle disease, your heart isn't working normally. As a result, your body retains fluids and you can have symptoms like shortness of breath, fatigue, and swelling. This happens because your heart muscle is changed by conditions or diseases. Most of these conditions weaken your heart little by little, over a period of time. Here's how heart failure starts and gets worse:

### How heart failure happens

With heart failure, initial damage **weakens** the heart muscle. See causes of heart failure on [page 6](#).



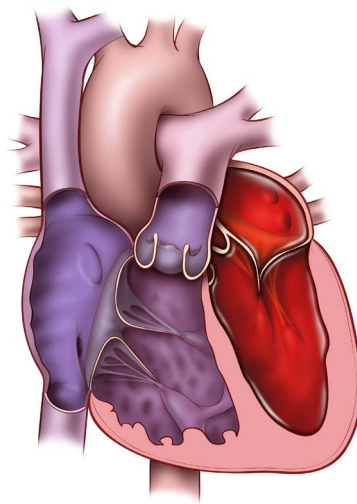
To make up for it, the body releases stress hormones. This causes your heart to beat faster and to **enlarge** (stretch or thicken).



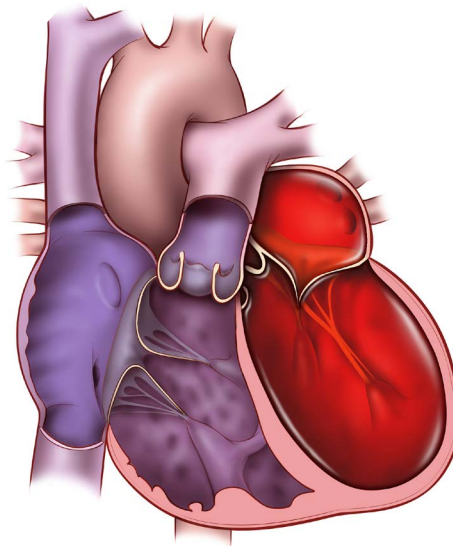
The result is poor forward flow and fluid back-up, which causes **symptoms** (fatigue, trouble concentrating, swelling, shortness of breath).



The heart muscle begins to wear out



Normal heart



Weak heart

### POOR ACTION VS. POOR RELAXATION

Your heart's pumping ability is often assessed using a measure called an **ejection fraction (EF)**. EF is the percentage of blood in the heart's pumping chamber that is pumped out (or ejected) with each beat.

- In a healthy heart, the left ventricle pumps out 55% to 75% of its blood with each beat. People with systolic heart failure usually have a lower ejection fraction.
- When the heart muscle is weak, it is called heart failure with reduced EF. This is when the EF is less than or equal to 40%
- In other cases, the heart can still pump effectively, but the muscle walls have stiffened. This keeps the heart from fully relaxing and filling with enough blood between contractions. Your healthcare team may call this diastolic heart failure or heart failure with preserved EF.

With both types of heart failure, your heart can't pump enough blood. This can interfere with the function of other major organs, and produce a range of symptoms throughout your body.

## WHY IS IT SOMETIMES CALLED CARDIOMYOPATHY?

Cardiomyopathy  
[car-dee-oh-my-AH-puh-thee]  
means heart muscle disease.  
Heart muscle disease  
from various causes can  
lead to heart failure.

cardio = heart  
myo = muscle  
pathy = disease

## What are the causes of heart failure?

Heart muscle damage of any type weakens the heart muscle and can lead to heart failure. The most common causes of heart muscle damage (often called **cardiomyopathy**) in the U.S. are listed below:

- **Atherosclerosis** [ath-er-oh-sklear-OH-sis]. Atherosclerosis, or coronary artery disease (CAD) is when the arteries that supply the heart with blood are narrowed or clogged. CAD reduces the amount of oxygen your heart receives and weakens the muscle. It can also cause a **heart attack** (called **myocardial** [my-oh-CAR-dee-ahl] **infarction** [in-FARK-shun], or **MI**). A heart attack can leave scar tissue on your heart. Unlike normal heart muscle, scar tissue doesn't contract (squeeze). Your heart may not pump as well. Heart muscle damage from CAD is typically called **ischemic** [is-SKEE-mik] **cardiomyopathy**.
- **High blood pressure (hypertension)**. Long-term, poorly-controlled high blood pressure makes your heart work harder to pump blood through your body. This is because high blood pressure increases the resistance your heart must pump against. Over time, all that extra work can wear out your heart and lead to heart failure. Heart muscle damage that is caused by high blood pressure is often called **hypertensive cardiomyopathy**.
- **Heart valve problems**. Heart valves control the direction of blood flow through your heart. When they're damaged, they often don't open and close properly. This can cause the blood to back up or can limit the forward flow of blood. Congenital [con-GEN-eh-tul] defects (defects present at birth) and infections such as rheumatic fever can cause heart valve problems that interfere with your heart's ability to pump blood effectively. This is called **valvular cardiomyopathy**.
- **Alcohol abuse**. Chronic, excessive alcohol intake can severely weaken the muscle walls of the heart. This problem is called alcohol-related heart failure, or **alcoholic cardiomyopathy**.
- **Drug use**. Use of some illegal drugs, such as cocaine or amphetamines, can damage the heart. Misuse of some prescription medications can also cause heart failure. And rarely, some cancer treatments can damage the heart. In these cases, the problem may be called **drug-induced cardiomyopathy**.

## What are the causes of heart failure? (continued)

- **Chemotherapy.** In some people, chemotherapy can cause heart muscle weakness, which may lead to heart failure. Let your doctor know if you have been treated for cancer.
- **Family health history (genetics).** Heart failure can also run in families—meaning it's in your genes. If you have a family history of heart issues, be sure to tell your healthcare team.
- **Unknown causes.** Sometimes the cause of heart failure is unknown. If tests and examinations cannot find a specific cause for the weakening of your heart, your healthcare providers will say that you have **idiopathic** [id-ee-oh-PATH-ik] **cardiomyopathy**.

## Notes



## WHY IS IT SOMETIMES CALLED CONGESTIVE HEART FAILURE (CHF)?

Your healthcare providers may refer to your condition as “congestive [con-JESS-tiv] heart failure,” or CHF. By adding the term “congestive,” they’re referring to the buildup of fluid (the congestion) that may occur with heart failure. This can cause symptoms like swelling and water weight gain.



### LESS COMMON SYMPTOMS:

Because everyone is different, you may have other symptoms, such as:

- Pressure in your chest (feeling like a band is around your chest)
- Skipping or racing heartbeat
- Fainting or nearly fainting
- Poor appetite

## What are the symptoms of heart failure?

Your heart failure symptoms are from fluid buildup, not enough output (flow of blood) from the heart, or lack of oxygen in your tissues. You may notice some — or all — of these heart failure symptoms:

- **Shortness of breath.** This can happen at any time, including when trying to sleep. You feel shortness of breath because of fluid buildup in your lungs. This makes it hard to breathe. You are likely to notice shortness of breath first during physical activity or at night when you're lying flat.
- **Cough.** Many people with heart failure complain of a frequent cough. Sometimes this cough is dry and hacking. Other times it produces phlegm [flem]. For some, this cough happens mostly at night. For others, it can last all day. Like shortness of breath, this cough is likely a side effect of fluid buildup in your lungs, especially if your phlegm has a little pink in it.
- **Extreme tiredness.** You will likely feel more tired than usual. You may also feel weak. This is because your heart can't pump enough blood to meet your body's needs. Your muscles and organs simply aren't getting the blood they need. Even a good night's sleep won't help.
- **Weight gain.** Weight gain may be one of the earliest signs of fluid buildup in your body. Extra fluid in your body translates into extra weight showing up on your scale. Each quart of extra fluid weighs about 2 pounds. This is why it's so important to keep track of your weight as part of your heart failure management.
- **Swollen ankles, feet, belly, lower back, and fingers.** Fluid buildup will show up as swelling in different parts of your body. It is most likely to show up in your ankles, feet, belly, lower back, and fingers. Swelling in your belly can cause you to feel bloated or nauseated, and can decrease your appetite. Swelling is usually worse at the end of the day.
- **Poor concentration and memory lapses.** Some people with heart failure complain of difficulty concentrating and lapses in memory. These symptoms may be explained by less oxygen being delivered to the brain.

There are many new tools available to help monitor your heart failure. Talk with your provider if you are interested in trying them.



# Diagnostic Tests

Heart failure can range from mild to severe. Your symptoms are one measure of your condition. They don't always tell the whole story. Your healthcare providers will want to do other tests to learn more about your heart failure. This will help them figure out the best treatment plan for your specific condition.

## Initial assessment

To see if you have heart failure, your healthcare providers will first ask you about your medical history, your family health history, your symptoms, and your health in general. They will also do a physical examination of your entire body, head to toe.

## Further assessment

Next, your healthcare providers may recommend additional tests to measure your heart function and determine the cause of your heart failure. During treatment, some tests might be repeated now and again to check your response to treatment. Some of these include:

- **Blood tests.** These include your red blood cell count and level of **electrolytes** (important elements like sodium and potassium). Blood tests can also check the function of your kidneys, liver, and thyroid. In some cases, blood tests can identify the cause of your heart failure.
- **Urinalysis.** Studying a sample of your urine (pee) will help find any problems with your kidneys or bladder that may be adding to your heart failure.
- **Chest x-ray.** An x-ray image of your chest shows the size of your heart and can show if fluid is building up in your lungs.
- **EKG (ECG, electrocardiogram [eh-lek-trow-CAR-dee-oh-gram]).** This test records the electrical activity of your heart and displays it on a screen for your healthcare providers to study. The procedure involves placing electrical wires with patches on your chest, arms, and legs.
- **Echocardiogram (echo).** **This is the easiest way to check your heart function.** An echo test uses sound waves (ultrasound) to see how well your heart is pumping and check the size of your heart.
- **Right heart catheterization** [cath-eh-teh-rye-ZAY-shun]. Some patients may need this test to check pressures in the heart, measure heart output, and check blood oxygen levels.



### HISTORY IS IMPORTANT

To fully understand your condition, your healthcare provider will ask about your health history. They will ask about:

- Your symptoms
- Habits
- Any other conditions and treatments
- If members of your family have had heart problems.

It's important to answer their questions as accurately and completely as you can.



## YOUR CARE TEAM

Many people will work together to diagnose and treat your heart failure and help you live better.

- **Your primary care provider.** This is the person you usually see for health problems. They may be a family practice physician, general internist, nurse practitioner, or physician assistant.
- **Your cardiologist.** This physician specializes in diseases of the heart and blood vessels.
- **Other heart specialists.** Other specialists may be involved, such as an electrophysiologist (who treats heart rhythm problems) or a cardiothoracic surgeon (if you need heart surgery).
- **Other healthcare professionals.** Many others may contribute to your care — such as physician assistants, nurse practitioners, nurses, dietitians, pharmacists, exercise physiologists, and care managers.
- **You and your family.** You and your family are at the center of this team! See the facing page for what you can do.

# Treatment

Heart failure is a chronic condition that in most cases cannot be cured. The good news is that heart failure CAN be managed and treated. The goals of heart failure treatment are to ease the workload on the heart, prevent further damage, and improve your heart's function, if possible. **For the best outcomes, you and your healthcare providers need to work together.**

## What your healthcare providers can do

### Diagnose and treat heart failure

Your healthcare providers will diagnose your heart failure, monitor your symptoms, and create a treatment plan for you. They may refer you and your family to a class or support group focused on living with heart failure.

### Prescribe and adjust medication

Nearly everyone with heart failure will need to take medication. The purpose of the medication is to lower the workload, strengthen the pumping action of your heart, and reduce fluid retention. These medications may also decrease your symptoms and increase your survival. Your team will check how well your medications are working and how well your body tolerates them. They will make adjustments as needed.

### Perform medical procedures, as needed

Some people benefit from surgery or other procedures such as implanted cardiac devices. Ask your provider for more information.

### Provide hospital treatment, as needed

The goal is to keep your heart failure as stable as possible, so you don't need to be treated in the hospital. However, you may need to be hospitalized to treat your heart failure at some point.

**If you're hospitalized,** your care will focus on removing excess fluid from your body. Before you leave the hospital, your team will take steps to help reduce your chance of having to return to the hospital. This will include:

- **Reviewing your ejection fraction (EF)** from your most recent echocardiogram. This is a key indicator of heart health.
- **Providing education** on the best way to take your diuretic (water pills) and **self-management for heart failure.** (See [page 11.](#))
- **Scheduling a follow-up appointment** within 7 to 10 days. Be sure to keep this appointment, even if you're feeling better.

## FOLLOWING UP

If you have to go to the hospital for treatment, you will likely get a follow-up phone call within 3 days after you go home. The call often comes from an automated call system.

You will be asked a few questions about how you are feeling. Be sure to answer this call. If you have concerns or are not feeling well, you can set up a chat with a nurse who can help.

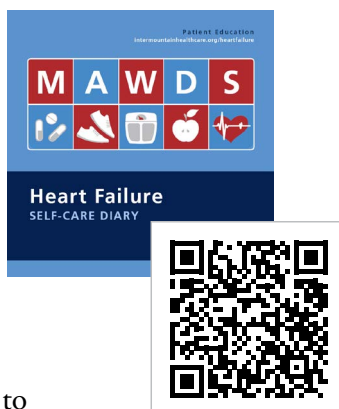
## What you can do

There are key parts of your treatment that are up to you. These include:

### Manage your lifestyle — using MAWDS

Lifestyle management is so important that most of this booklet focuses on this part of treatment. Intermountain's plan for lifestyle management is called MAWDS. **MAWDS** stands for:

- M** Take your **MEDICATIONS**
- A** Stay **ACTIVE** each day
- W** **WEIGH** yourself each day
- D** Follow your **DIET**
- S** Recognize your **SYMPTOMS**



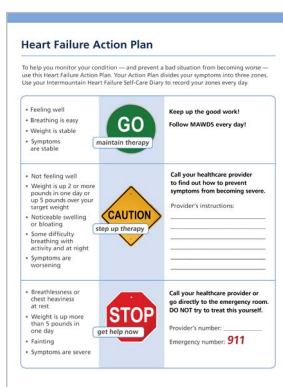
Pages 12 to 28 provide more details on how to use MAWDS to manage your heart failure.

### Monitor for changes daily

Keep track of your symptoms in your **Heart Failure self-care diary** and watch out for changes. Your providers can show you how to use this.

### Communicate with your healthcare providers

Let your healthcare providers know if your condition changes. See the Heart Failure Action Plan on **page 35** to know when you should call. It's important to call before your condition gets worse.



## A FAMILY AFFAIR

Have a frank discussion with your loved ones about how they can help you improve your health. Their support goes a long way toward helping you manage your heart failure. It can also help THEM, giving them a role to play and a sense of control. They can help by:

- **Reminding you to take your medications.** Taking your medications on schedule is key to managing your disease.
- **Keeping records and notes.** Loved ones can help you keep activity and weight records and write questions to ask your healthcare provider.
- **Exercising with you.** Having friends or family exercise with you can help you stick to an appropriate activity schedule.
- **Supporting you in heart-healthy eating.** They can help you eat properly by shopping for, cooking, and eating low-sodium foods with you.

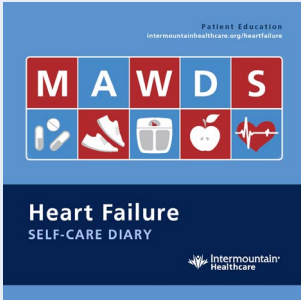
Talk with your family about an advance directive. An advance directive is a document that lists your decisions for your care if you can't speak for yourself.

See [intermountainhealthcare.org/directives](http://intermountainhealthcare.org/directives) to learn more.



# Lifestyle Management

This section of the book focuses on lifestyle management with a **MAWDS** plan. It starts with medication.



To help you follow this plan, use your **Heart Failure Self-Care Diary** every day (if available in your area).



As you learn about your medications, write down any instructions in your own words — and get your healthcare provider to double-check your notes.



## Take your medication

Your healthcare providers can prescribe your medications, but it's up to you to take them properly. You also need to communicate with your healthcare providers about your medications. They need your feedback to understand how you're responding to treatment and make any necessary adjustments.

Your medications are proven to help improve your quality and length of life. It's vital that you take your medications exactly as prescribed. Missing a dose, or taking too much, can cause serious problems. **In fact, not taking your medications as instructed is one of the most common reasons people with heart failure need to be hospitalized.**

Be sure to pay attention to changes made in your medications, and keep an updated medication list with you at all times so you take them as directed.

## Medication matters

Research shows that medications can:

- Decrease symptoms and keep you out of the hospital
- Increase your tolerance for physical activity
- Keep you healthier, longer

If you can't afford your medications, check with your healthcare provider or pharmacist. There may be less expensive forms to try or ways to help you get your medications.

## Tips for taking your medication safely and consistently

- **Make sure you know exactly how to take your medications.** Always ask your healthcare providers these questions:
  - When should I take each medication?
  - How much should I take each time?
  - Are there any special instructions, such as taking a pill with a meal or on an empty stomach?
  - Are there side effects I should watch for?
- **Tell your healthcare providers about any other medications you're taking.** This will help your care team make sure there are no harmful interactions between drugs.
- **Talk to your healthcare provider before taking any over-the-counter medications or other supplements.** These can interact with your regular medications. Do not take any new substances without first talking to your healthcare providers. This includes pain relievers (such as aspirin, ibuprofen, and naproxen) and any herbal, vitamin, or mineral supplements.
- **Talk to your healthcare provider about what to do if you accidentally skip a dose.** Everyone forgets sometimes, so be prepared. Don't try to make up for a missed dose by taking 2 doses at once (unless your healthcare provider specifically tells you to do so).
- **Don't skip a dose because you feel better.** Most heart failure medications must be taken regularly to keep you stable.
- **Develop a routine to take your medications.** For example, it might help to take your medications right after brushing your teeth in the morning or while watching the evening news.
- **Set an alert to remind you when it's time to take your medications.** Or, use an electronic medication reminder.
- **Organize your pills.** Use a divided pillbox for different times of the day or different days of the week. Some pillboxes even have a built-in alarm to remind you when to take your pills.
- **When you have 7 to 10 days of medications left, order more.** Pharmacies sometimes have a delay in filling orders, and it's important to avoid running out of your prescription. Consider signing up for auto-refill for your medications.
- **Carry a card.** Keep a written list of all your medications and dosages in your wallet or purse. Keep a list of any medical allergies with this list.



### A SHOT NEVER HURTS

To help support your treatment — and keep you from getting sick — your healthcare providers may recommend the following:

- **A COVID vaccine.** The COVID vaccine may help you avoid severe symptoms and a hospital stay.
- **An annual flu shot.** Influenza vaccines can help you avoid the year's worst flu.
- **A pneumococcal vaccine.** A "pneumovax" can help protect you from pneumonia, meningitis, and other serious infections.

Other vaccines may also be recommended.

## Medication examples

The tables on this page and the next list a few examples of each medication type, what they do, and possible side effects. (Generic names are in lower case and brand names start with a capital letter. Your doctor will prescribe generics when appropriate.) **Severe side effects are rare — call your provider right away if you have a severe side effect.**

TYPE*	EXAMPLES	WHAT THEY DO	SIDE EFFECTS
<b>Diuretics</b> ("water pills")	bumetanide (Bumex), furosemide (Lasix), metolazone (Zaroxolyn), torsemide (Demadex)	Relieve stress on the heart, improve heart function, reduce symptoms, prevent hospitalization, and improve survival rates.	<ul style="list-style-type: none"> <li>• Common: Increased urinary frequency, upset stomach, dizziness</li> <li>• Severe: Large rash, kidney dysfunction</li> </ul>
<b>Mineral supplements</b>	magnesium oxide, potassium (K-Dur, K-tab, K-Lyte, Micro K, Slow K, Klor-con)	Replace potassium or magnesium that may be lost with diuretics.	<ul style="list-style-type: none"> <li>• Common: Upset stomach, diarrhea</li> </ul>
<b>Angiotensin-converting-enzyme (ACE) inhibitors,</b> <b>Angiotensin II receptor antagonists (ARBs),</b> <b>or ARNI (ARB + Neprilysin Inhibitor)</b>	<b>ACE inhibitors:</b> captopril (Capoten), enalapril (Vasotec), fosinopril (Monopril), lisinopril (Prinivil, Zestril), quinapril (Accupril), ramipril (Altace) <b>ARBs:</b> candesartan (Atacand), losartan (Cozaar), valsartan (Diovan) <b>ARNI:</b> Sacubitril-valsartan (Entresto)	Block stress hormones and decrease the pressure in blood vessels, so it is easier for the heart to push blood forward.	<ul style="list-style-type: none"> <li>• Common: Dry cough (ACE inhibitors), dizziness, headache</li> <li>• Severe: Swollen tongue or lips, kidney dysfunction</li> </ul>
<b>Beta blockers</b>	bisoprolol (Zebeta), carvedilol (Coreg, Coreg CR), metoprolol succinate (Toprol XL)	Relieve stress on the heart, improve heart function, reduce symptoms, prevent hospitalization, and improve survival rates.	<ul style="list-style-type: none"> <li>• Common: Dizziness, fatigue</li> <li>• Severe: Large rash, masked signs of low blood glucose in diabetes, worsening of asthma or COPD</li> </ul>
<b>Aldosterone receptor antagonists</b>	spironolactone (Aldactone), eplerenone (Inspra)	Help rid the body of excess fluids and prevent loss of electrolytes. Improve survival rates and reduce risk of hospitalization.	<ul style="list-style-type: none"> <li>• Common: Upset stomach, diarrhea, breast pain (spironolactone)</li> <li>• Severe: Trouble breathing, rash, swollen tongue or lips</li> </ul>
<b>SLGT2 Inhibitors</b>	canagliflozin (Invokana), dapagliflozin (Farxiga), empagliflozin (Jardiance)	Reduces blood glucose. Typically prescribed for diabetes. More recently proven to be beneficial in patients with Heart Failure, even in those without diabetes.	<ul style="list-style-type: none"> <li>• Common: Urinary or yeast infection, thirst, dehydration</li> <li>• Severe: Rash or hives, difficulty breathing or swallowing, swelling in mouth, lips or tongue, nausea, vomiting, stomach pain, groin infection</li> </ul>
<b>Anticoagulants</b> ("blood thinners")	heparin, warfarin (Coumadin), enoxaparin (Lovenox), apixaban (Eliquis), rivaroxaban (Xarelto), dabigatran (Pradaxa)	Help prevent blood clots from forming or getting larger.	<ul style="list-style-type: none"> <li>• Common: Minor bleeding (gums, nosebleeds, bruising), upset stomach, nausea/vomiting</li> <li>• Severe: Major bleeding (a sign is black tarry stools)</li> </ul>



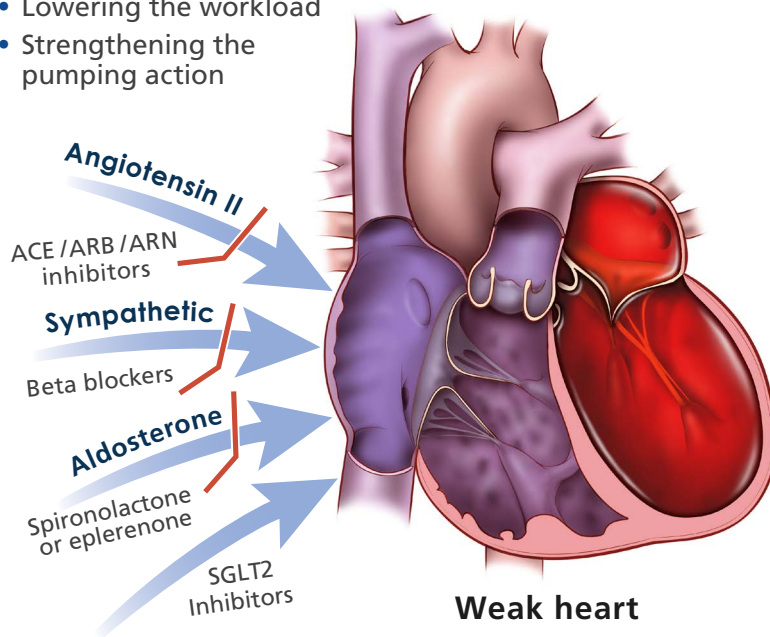
## Medication examples (continued)

TYPE*	EXAMPLES	WHAT THEY DO	SIDE EFFECTS
<b>Alternative vasodilators</b>	hydralazine (Apresoline), isosorbide mononitrate (Imdur, ISMO, Monoket), isosorbide dinitrate (Isordil Titrados, Dilatrate-SR), hydralazine/isosorbide dinitrate (BiDil)	Decrease the pressure in blood vessels.	<ul style="list-style-type: none"> <li>• Common: Headaches, fast heartbeat, dizziness, swollen feet or ankles</li> <li>• Severe: Severe tiredness, serious rash, chest pain</li> </ul>
<b>Digitalis</b>	digoxin (Lanoxin)	Helps irregular heart rhythms and also helps improve exercise tolerance a bit. Reduce risk of hospitalization.	<ul style="list-style-type: none"> <li>• Common: Upset stomach, nausea /vomiting, headache, dizziness</li> <li>• Severe: Confusion, irregular heartbeat, mental disturbance</li> </ul>
<b>Inotropes</b>	dobutamine (Dobutrex), milrinone (Primacor)	<p>Strengthens the heart's pumping action.</p> <p>Started in the hospital with an IV, inotropes are usually used to treat severe symptoms. Used while waiting for mechanical support or heart transplant, or near the end of life.</p>	<ul style="list-style-type: none"> <li>• Common: Headache, tremors, fever, easy bruising, fast heartbeat, irregular heartbeat</li> <li>• Severe: Chest pain, dizziness, difficulty breathing, weakness</li> </ul>

\*Some patients with HFrEF (reduced ejection fraction) may be prescribed "Quad Therapy." This is a combination of 4 medications: an ACE /ARB or ARNI, a beta blocker, an aldosterone receptor antagonist, and a SGLT2 inhibitor. Quad therapy is used to improve symptoms, quality of life, and survival. Discuss these medications with your care team.

### Heart failure medications can help the heart by:

- Blocking hormones
- Lowering the workload
- Strengthening the pumping action



### Where can I learn more?

You can learn more about these medications at [medlineplus.gov/druginformation.html](https://medlineplus.gov/druginformation.html)



Take your medications every day and never skip doses. Contact your health provider if you experience symptoms such as low blood pressure or increased fatigue.

## STARTING UP

Don't get discouraged if you find you can only be active for a short period of time. Some people can only exercise 5 minutes a day at first. The important thing is to start your activity plan and stick to it. You can build up your activity level slowly over time.

## THE BEST REASON TO EXERCISE?

You'll feel better! Need more reasons? Research shows that heart failure patients who follow approved exercise plans strengthen their hearts, have fewer hospital visits, and enjoy better outcomes.



# MAWDS

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## ACTIVITY



## Stay active each day

People with heart failure often have questions about the safety and benefits of physical activity. This section provides some basic guidelines.

### Benefits of exercise

Even though you have heart failure, you **can** enjoy physical activity and exercise. In fact, you **should** stay active. A little exercise can make a big difference in your health. Here are a few of the benefits you can expect from regular activity:

- Improved heart function
- Stronger muscles, so everyday tasks aren't as tiring
- Help in maintaining your weight (or losing weight if needed)
- Increased energy
- Better sleep at night
- Improved mood and outlook

### The “best” exercise plan

The best exercise plan is one that is right for your current health, habits, and interests. Make sure to speak with your healthcare providers before starting any activity or exercise plan. They can help you find an exercise level that's right for you. They may also tell you whether to avoid certain types of exercises.

The Centers for Medicare and Medicaid Services pays for cardiac rehabilitation services for patients who have an ejection fraction (EF) of less than 35%. Cardiac rehabilitation connects patients with highly trained exercise therapists who will create an exercise program that can help reduce symptoms and improve their quality of life. Ask your healthcare provider if you qualify.

Most people can choose from a range of safe activities and exercises. Daily walking, swimming, and biking are all great forms of exercise. You can do these activities at an intensity that matches your fitness level. The key is to pick an activity that you enjoy. This way, you're more likely to do it more often and over the long term.

Keep in mind that regular activity is your goal. You should start slowly and increase the time and level of activity gradually. You'll likely have good days and bad days. Listen to your body and learn your limits. Adjust your activities as needed.

## Staying safe while exercising

What if you don't really know your physical limits yet? How can you be sure you're exercising safely?

First, follow the general guidelines from your healthcare providers about the amount and type of activity that's right for you. Be sure to pay attention to your body's reaction to activity. Make sure you can carry on a conversation during exercise, and that you're not exhausted the next day. Always include regular periods of rest in your daily schedule. Stop and rest whenever you feel tired or short of breath.

Stop exercising and consider calling your healthcare provider if you have any of the following warning symptoms:

- Pressure or pain in your chest, neck, arm, jaw, or shoulder
- Dizziness or lightheadedness, passing out
- Nausea
- Unusual shortness of breath
- Unusual tiredness
- Fast or slow heartbeat
- Irregular heartbeat



### **BREATHE EASY, LIFT LIGHT**

Avoid activities that require you to hold your breath or lift heavy weights. Such activities put extra pressure on your weakened heart. Ask your doctor how much weight is safe to lift.



## SAFE SEX?

People with heart failure often wonder whether — and when — they can safely get back to sexual activity. Healthcare providers believe that you can have sex as soon as you feel able. The physical effort of sexual activity is comparable to walking up 2 flights of stairs at a moderate pace. (Most people agree that the stairs are less fun!)



## TALK YOUR WALK

A good guideline to ensure you're exercising within your limits is to make sure you can carry on a conversation during activity.

## STAY CLEAR FROM SMOKE!

Smoking is dangerous, especially if you have heart disease. Not only can smoking speed the progression of heart disease, but it also puts extra strain on your struggling heart and decreases the amount of oxygen in your blood. Even second-hand smoke can have these effects.

- **If YOU smoke, QUIT!** Ask your healthcare provider for information and resources on quitting smoking — such as Intermountain's booklet *Quitting Tobacco: Your Journey to Freedom*. For more information, visit [intermountainhealthcare.org/prevention](https://www.intermountainhealthcare.org/prevention), or call the Tobacco Quit Line at 1-888-567-TRUTH.
- **Keep your home smoke-free.** It may be hard at first to tell people not to smoke in your home. Help them understand that it's for your health. If they must smoke, ask them to do so outside.





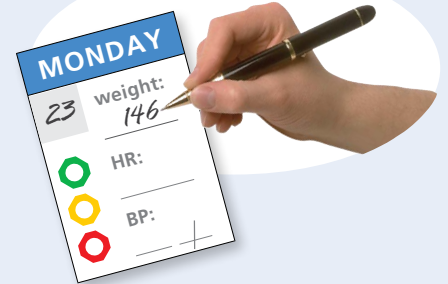
## Weigh yourself each day

Every morning, you can take one of the most important steps toward controlling your heart failure symptoms: stepping on your scale. Weighing yourself daily and keeping a record will help you and your healthcare providers know if your heart failure is under control. Rapid changes in your weight can mean you are gaining or losing fluid.

## Your weight and your heart

As you learned from the first section of this guide, heart failure causes fluid buildup in your body. This fluid shows up as extra weight on your scale.

Generally speaking, the more severe your heart failure, the more fluid buildup in your tissues. An increase in your weight could mean a downturn in the condition of your heart. For this reason, you need to monitor your daily weight as a measure of your heart's health.



**Write down your daily weight faithfully and accurately.** You want a detailed record of your body weight pattern, not just a general idea.

Your healthcare providers can help you determine your **target weight**. Your target weight is how much you weigh when you're NOT retaining fluid.

## Use the Heart Failure Self-Care Diary daily

**1** At the beginning of a new month, write in your target weight and the month at the top of the page.

**2** Write in the day of the month in the square in each box.

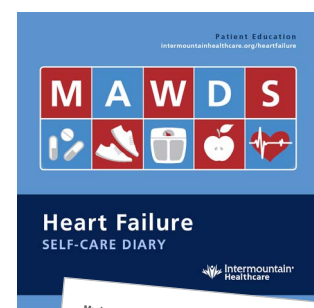
**3** Put a check in the zone you are in for the day (see page 31).

MONDAY	
23	weight: 146
✓	HR: 79
○	BP: 120/80
○	

**4** Each day record your weight.

**5** Record your heart rate.

**6** Record your blood pressure.



## WHEN YOU'RE GAINING WEIGHT

When your weight goes up, it could mean that you're gaining weight in fluids or fats.

Fat weight gain happens more slowly than fluid weight gain.

Talk with your healthcare provider to determine why you're gaining weight and if you need to change your treatment plan.



## WHEN YOU'RE LOSING WEIGHT

When your weight goes down, it could mean you're not getting enough to drink.

Talk with your healthcare providers to figure out why you're losing weight and if you need to change your treatment plan.

## Is there a right way to weigh myself?

Weighing yourself is as simple as stepping on the scale, but there are a few things you can do to ensure your daily record is accurate and complete:

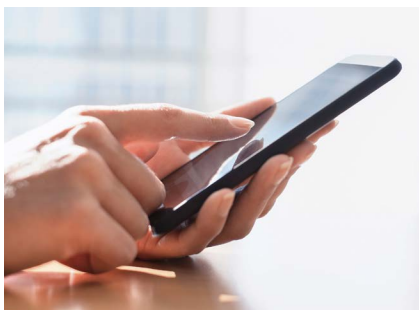
- Use the same scale every day.
- Weigh yourself at the same time every morning. Do it after urinating (peeing) but before eating or drinking.
- Weigh yourself when you're dry, not wet from a shower or bath.
- Write down your daily weight faithfully and accurately. You want a detailed record of your weight pattern, not just a general idea. Use your Intermountain **Heart Failure Self-Care Diary** or a mobile application (app) and take it with you to your healthcare appointments. Ask your healthcare provider for a copy of the diary or a recommendation for an app.

## When should I call my healthcare provider about my weight?

Call your healthcare provider if you see either of these weight-gain warning signs:

- You gain more than 2 or 3 pounds in one day
- You are 5 pounds over your target weight

These signs could mean that your body is retaining fluid, and may warrant a change in your treatment plan. You should also call if you have any questions about your target weight, or any other aspect of your management plan.



Call your healthcare provider if you gain more than 2 or 3 pounds in one day or are 5 pounds over your target weight.

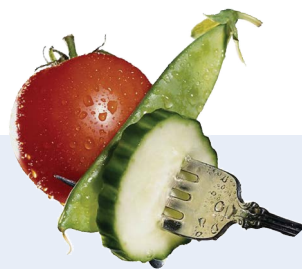
**Remember to follow  
MAWDS  
every day!**



# MAWDs

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## DIET



## Follow your diet

When you're diagnosed with heart failure, you'll need to make 3 important adjustments to your diet:



### 1 Salt

Lose your salt shaker!  
Eat less than 2 grams  
(2,000 mg) per day.



### 2 Fluids

Limit your intake to less than  
8 cups (64 ounces, or 2 liters)  
per day.



### 3 Alcohol

Generally, avoid alcohol —  
especially if it caused your heart  
failure. If you do drink alcohol,  
limit it to one beer, cocktail, or  
glass of wine now and then.

## HEALTHY ADDITIONS

While you're working on your diet goals, be sure you are adding healthy foods for balance. This means eating moderate amounts of:

- Fresh and dried fruits and vegetables
- Low-fat, low-salt cheeses
- Cooking oils such as olive, canola, and safflower oil
- Fresh fish, chicken, and turkey
- Lean cuts of beef, veal, pork, and lamb
- Breads, cereal, grain, and other starches (potatoes, pasta)

## SPECIAL PLANS FOR SPECIAL CONDITIONS

If you have other health conditions (such as diabetes or chronic kidney disease) you may need a special eating plan.

Meet with a dietitian for details and advice.

You may also need to make other adjustments in the way you eat and drink. These adjustments can ease your heart's workload and help you feel better. A care provider or dietitian can give you specific guidelines and suggestions.

## THE SALT CONNECTION

In a person with a healthy heart, salt is removed from your body when you pee. But when your heart is weakened, your body has trouble getting rid of salt. Too much salt can cause:

- **Water (fluid) retention.** Fluid retention can cause shortness of breath and swollen hands and feet. In this case, your heart has to work extra hard to pump the excess fluid.
- **Increased blood pressure.** This also means more work for your heart.

## TRIPLE TROUBLE

The average American eats about 6,000 mg of salt a day. This is three times the amount the average person actually needs.

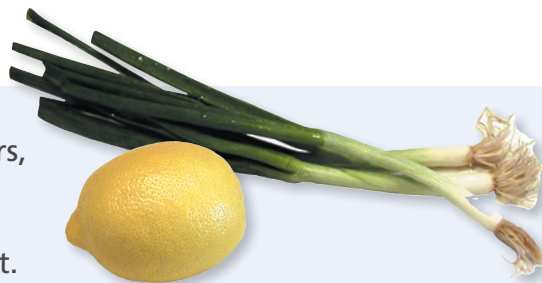


## 1 Limit salt in your diet

Most healthcare providers will recommend that you eat less than 2,000 mg of salt (sodium) per day. To meet this goal, you'll need to follow a low-salt (low-sodium) diet. In addition to following the guidelines given by your healthcare providers, you should develop the following habits as part of your low-salt diet:

- **Take the salt shaker off the table.** If it's not there, you can't use it!
- **Use other spices instead of salt in your cooking.** Try these flavor enhancers: allspice, dill, lemon, onion, curry, pepper, and garlic powder (not garlic salt). If you want to try salt substitutes, ask your healthcare providers which are safest.
- **Choose fresh or frozen vegetables instead of canned foods.** Canned foods often contain salt.
- **Rinse canned foods for 30 seconds.** If canned vegetables are all you have at hand, you can reduce the salt content by a third by rinsing the canned food with water and allowing it to drain before heating and eating.
- **Avoid processed meats.** Foods such as hot dogs, salami, bacon, and other lunch meats usually contain a lot of salt.
- **Stay away from salty snacks** like potato chips, salted nuts, and pretzels.
- **Cut out headache or heartburn medications** that contain salt in the form of **sodium bicarbonate** or **sodium carbonate**. (The labels will tell you whether sodium is an ingredient.)
- **Choose foods labeled "unsalted," "no salt added," or "low sodium."** You'll be pleasantly surprised that many of your favorite foods also come in low-salt versions.
- **Take time to read and compare food labels.**
- **Ask that your food be prepared with less salt (or no salt) when eating out.**

Use flavor enhancers, such as lemon or onion, as a replacement for salt.

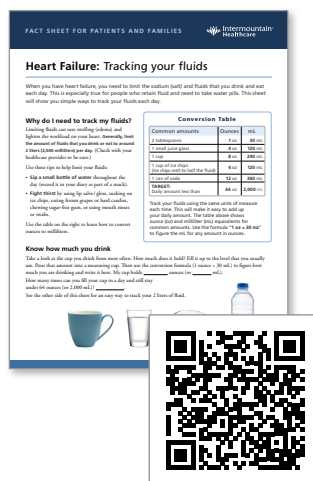


## 2 Limit your fluid intake

Another way to reduce the fluid retention caused by your heart failure is to drink less fluid — only 8 cups a day (64 ounces, or about 2 liters). Keep in mind that feeling thirsty doesn't mean your body needs more fluid. Instead of drinking fluids when you're thirsty, try:

- Chewing gum
- Sucking on ice chips or hard candy
- Rinsing your mouth with water

The table below shows an example of how your fluid intake can add up to 64 ounces (about 2 liters) a day. As you can see, this still allows you to drink a fairly normal amount of fluid each day. Intermountain's **Heart Failure: Tracking your fluids** fact sheet can help you record your fluids and add up your total each day.



Here's a sample of how fluids can add up to your limit of 64 ounces (about 2,000 mL or 2 liters):

MEAL	FLUIDS	OUNCES	mL
Breakfast	1 cup milk (8 ounces), 1 cup tea (8 ounces)	16 oz.	480 mL
Lunch	1 glass water (10 ounces), 1 cup soup (8 ounces)	18 oz.	540 mL
Snack	1 can soda (12 ounces)	12 oz.	360 mL
Dinner	1 glass water (10 ounces), 1 cup watermelon (8 ounces)	18 oz.	540 mL
DAILY TOTAL		64 oz.	1,920 mL (about 1.9 liters)

## 3 Limit alcohol

Here are a couple of good reasons to limit your alcohol intake:

- It helps limit your fluid intake to reduce the strain on your heart.
- It prevents heart muscle damage that may be caused by more-than-moderate alcohol use.

According to the American Heart Association, women should have no more than 1 drink each day (a beer, glass of wine, or cocktail) and men should have no more than 1 to 2 drinks each day. (Note: if alcohol caused your heart failure, stay away from alcohol completely.)

## RE-THINKING WATER DRINKING

In general, drinking water is good for you. But it's a myth that everyone should drink a lot of water to "flush out the kidneys." And the common prescription to "drink more water" does NOT apply to people with heart failure.

To ease symptoms, people with heart failure need to limit — not increase — the fluids they take in.



## WHEN LIGHT IS WRONG

Don't be fooled by "light" labels on foods. A "light" label only refers to the amount of fat in a food — not the amount of salt. Many low-fat or fat-free foods are actually quite high in salt! Check the label before buying.

## WHEN FOODS ARE FLUIDS

You'll need to count some foods as fluids in your diet. Such foods include:

- Soup
- Sherbet and ice cream
- Gelatin
- Watermelon
- Iceberg lettuce
- Other fruits and vegetables that contain a lot of fluid

## Diet tips

### Buyers beware!

When buying prepared, canned, or packaged foods, be sure to read the label. This will help you stay within your daily "budget" of 2,000 mg of sodium per day. For example, look at the soup label below:

#### Nutrition Facts

Serving Size 1 cup (239g)

Servings per container **about 2**

#### Amount per Serving

**Calories** 100    **Calories from Fat** 15

% Daily Value \*

**Total Fat** 2.5g    2%

Saturated Fat 1g    0%

Trans Fat 0.5g

**Cholesterol** 15mg    5%

**Sodium** 850mg    **35%**

**Total Carbohydrate** 15g    5%

Dietary Fiber 1g    4%

Sugars 1g

**Protein** 7g

#### Watch out!

The nutrition facts are for just one serving.

This can of soup contains **2 servings** at **850 mg** of sodium each. Eating the entire can by yourself would use up almost all of your sodium budget for the day (one can = 1,700 mg sodium).

Your choices: Skip this soup in favor of a lower-sodium alternative, or limit your portion to a single serving — or even half a serving.

Or better yet, make a homemade version that is salt-free.



## Eating out

You can still enjoy eating out if you have heart failure. It just requires a little extra thought and flexibility. Follow these 3 guidelines whenever you eat out:

- 1 Make smart menu selections
- 2 Ask for a “special order” (such as no salt)
- 3 Keep portion sizes small

See below for heart-healthy tips on how to use these guidelines while eating out and living well.

### Make smart menu selections

Knowing a few cooking terms can help you make healthy choices at a restaurant. The terms below describe ingredients and preparation methods, and help you make better selections from the menu.

CHOOSE entrees that are described this way:	AVOID foods that are described this way:
<ul style="list-style-type: none"><li>• Steamed</li><li>• In its own juice</li><li>• Garden fresh</li><li>• Broiled</li><li>• Roasted</li><li>• Poached</li><li>• Lean</li></ul>	<ul style="list-style-type: none"><li>• Buttery, with butter, in butter sauce</li><li>• Creamed, creamy, cream sauce, gravy, hollandaise</li><li>• Parmesan, au gratin, cheese sauce, scalloped</li><li>• Sautéed, fried, pan fried, crispy, braised</li><li>• Breaded, stuffed</li><li>• Casserole, hash, pot pie</li><li>• Marinated (in oil), basted in butter, with gravy, in brine</li><li>• Prime (the grade of meat with the most fat)</li></ul>



### KEEP IT SIMPLE

For the heart-healthiest meals, choose foods in their simplest forms. For example, skinless chicken breast is a better choice than chicken salad, and a broiled fish fillet is a better choice than stuffed fish.



### MENU TIP-OFFS

The table on the right can help you avoid high-sodium foods and also foods that are high in fat and calories. Remember, keeping your weight down will also help you manage your heart failure!



## SELECT YOUR SALAD SENSIBLY

A trip to the salad bar can make it easier to get all your daily vegetables and fruits and also fill you up. However, watch out for salad dressings which may contain a lot of salt and fat. Also watch out for salty, fatty meats and cheeses. Limit these items, or choose healthier alternatives.

Each time you eat out, for every meal or special occasion, there are some things to consider:

- **Breakfast.** When you're eating breakfast out, order items like oatmeal, eggs sunny-side up, toast with jelly, juice, skim milk, and a banana. Avoid breakfast meats. Also, watch out for waffles and pancakes. They are hidden sources of sodium.
- **Lunch.** Sandwich shops are a good choice for heart failure patients since you can have your lunch made to order. Start with whole wheat, rye, sourdough, or pumpernickel bread. Select grilled or fresh meats, not processed meats. Add vegetables, such as lettuce, grilled vegetables, tomatoes, onions, and fresh (not pickled) peppers.
- **Snacks.** Watch out for high-sodium chips and crackers. Choose other crunchy finger foods like carrot and celery sticks, fresh fruit, or lower-sodium snacks.
- **Dessert.** Choose fresh fruit or frozen desserts that are low in sodium and fat. For example, choose ices, sorbets, sherbet, and fat-free frozen yogurts and ice cream. Request your frozen dessert in a bowl rather than a cone (cones add sodium). Hold the nuts and rich toppings (fudge, butterscotch).
- **Delivery.** If you call out for pizza, you'll need to order carefully. Watch out for the high-sodium tomato sauce, pepperoni, and cheese. Instead, choose toppings like ricotta cheese and vegetables.
- **Drive-through.** Fast food isn't your best option. If you use the drive-through, choose healthier items such as salad or broiled chicken breast. Ask for the nutrition facts on your meal, and say no to fries or "supersized" items.



## Ask for a special order

Keep in mind that you can always ask your server about ingredients and cooking methods. You shouldn't have to guess. You can also ask your server if a particular dish can be prepared in a heart-healthy way. For example, many restaurants will be happy to prepare a meal without salt. They will steam foods rather than fry them. And you can ask them to serve sauces, gravies, and dressings "on the side."



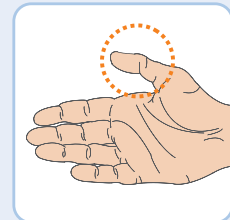
## ✓ Keep portion sizes small

Americans tend to eat big meals. To help control your portions, use the guidelines in this table:

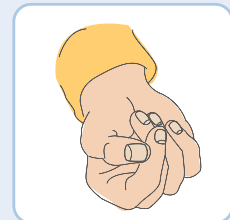
FOOD	LIMIT portion size to:
Lean meat, fish, poultry (boneless)	3 ounces (the size of your palm or a deck of cards)
Bread	1 slice
Cereal, ready-to-eat	$\frac{3}{4}$ cup – 1 cup
Cereal, cooked without salt	$\frac{1}{2}$ cup
Fresh fruit	1 medium (the size of a tennis ball), or 1 cup cut up
Fresh juice*	$\frac{3}{4}$ cup
Milk (skim is best)*	1 cup
Vegetables, cooked	$\frac{1}{2}$ cup
Vegetables, raw (including salad greens)	1 cup
Pasta, rice, or other cooked grains	$\frac{1}{2}$ cup
Baked potato	$\frac{1}{2}$ large potato
Mashed potatoes	$\frac{1}{2}$ cup
Lite or fat-free sorbet, sherbet, yogurt, or ice cream*	$\frac{1}{2}$ cup

\* These are counted in your total fluid intake.

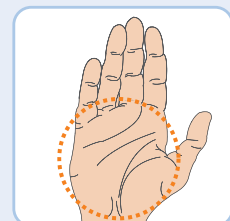
To help you judge portions, use these “handy” formulas:



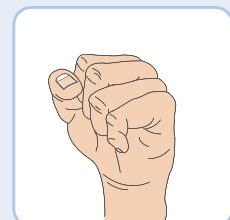
**thumb =  
1 ounce**



**handful =  
1 to 2  
ounces**



**palm =  
3 ounces**



**fist =  
1 cup**



## COPING WITH SYMPTOMS AND STRESS

As you learn to pay attention to your physical health, don't neglect your emotional health. With a chronic disease like heart failure, you can expect good and bad days and the feeling that you're riding an emotional roller coaster. You'll manage ALL your days better if you acknowledge and learn to cope with the stress that heart failure can bring to you and your family.

# MAWDS

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## SYMPTOMS



## Recognize your symptoms

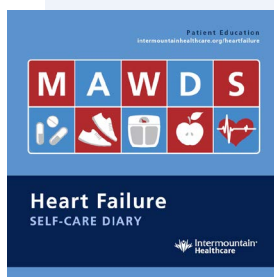
As you learn to manage your heart failure with the MAWDS plan, you'll soon be aware of how important YOU are in maintaining your health. The last part of MAWDS is learning how to recognize your heart failure symptoms and take appropriate action. (See the **Heart Failure Action Plan** on page 31 for a list of heart failure symptoms and what to do.)

## What if my symptoms get worse?

It's your job to pay attention to your symptoms and tell your healthcare providers about any changes. This way, they can make any necessary adjustments in your treatment before your symptoms become too severe. This can prevent unnecessary trips to the hospital.

## What if I have no symptoms?

It's possible to have heart failure without symptoms such as fatigue or shortness of breath. **Just because you don't have symptoms, this does not mean that you can ignore your diagnosis and treatment plan.** Instead, like all other heart failure patients, you need to follow every aspect of your treatment plan. This includes taking prescribed medications to prevent the progression of your heart disease.



## DEAR DIARY...

Use your Intermountain **Heart Failure Self-Care Diary** to help you monitor your symptoms and keep you on the right track with every aspect of your MAWDS plan. Even if you don't notice any symptoms, continue to follow your MAWDS treatment plan faithfully. Ask your provider for a copy and review your trends at each office visit. (Diary may not be available in all areas)

# Facing Your Future

It will take time to understand and accept what it means to have heart failure. You'll probably feel a range of emotions. Your outlook on the future may also change, depending on your health status. Heart failure can range from mild to severe, and each person responds differently to treatment. For some, heart failure symptoms are reversible with proper treatment. For others, symptoms get worse over time, passing through the stages shown on the next page.

## Accepting your diagnosis

Given the uncertainty of your diagnosis, it's natural, and even healthy, to grieve. Managing your feelings about heart failure is an important aspect of taking care of yourself. The emotional stages you may expect after a diagnosis of heart failure are described below.



### YOUR INITIAL REACTION

Your initial reaction may be shock, disbelief, denial, or numbness. For the first few months, you may have a hard time acknowledging your condition. It's tough to be told you have heart failure. It's a new and unwelcome companion to your life.



### ADJUSTING TO YOUR CONDITION

For 3 to 12 months after your diagnosis, you may experience preoccupation, fear, anxiety, anger, or hopelessness. During this time, you may struggle to integrate new routines — and a new sense of responsibility — into your daily life. Yet from questions of “why me?” and “what if?”, you will probably move gradually toward more acceptance of your condition.



### NEW HABITS BECOME ROUTINE

Finally, when new habits become routine and your understanding of heart failure improves, you'll probably begin to feel more peaceful about your diagnosis. You may get satisfaction from the adjustments you've made in your life, and feel new resolve and hope about the future.

Be patient with yourself as you go through these emotional stages. Adjusting to life with heart failure isn't easy. However, many people have learned to accept their diagnosis and to lead lives filled with a renewed sense of purpose and hope. With time, support, and patience, you can too.



## PREVENTING RE-HOSPITALIZATION

You may need to be hospitalized for heart failure at some point, but there are ways to avoid returning to the hospital for additional treatment. Below are the most common reasons people return to the hospital, and how to prevent them:

- **Running out of medications, or not taking them correctly.** Prevent this by faithfully following your medication plan.
- **Taking in too much salt or fluid.** Prevent this by following MAWDS every day.
- **Medical conditions** such as infection, high blood pressure, or heart rhythm problems. To help prevent re-hospitalization, follow your doctor's directions to manage these conditions.
- **Using non-steroidal anti-inflammatories (NSAIDs),** such as ibuprofen, aspirin, and Aleve. These types of pain relievers can add to fluid retention. Don't take them without talking to your healthcare provider.
- **A heart attack, or the progression of heart failure** (see the table at left). Keep appointments with your provider and follow your treatment plan to keep your heart failure stable.

## Understanding the stages of heart failure

When you are diagnosed, your doctor will determine the severity of your disease. Heart failure often progresses through 4 stages. Your treatment options will vary at each stage. Knowing these stages will help you understand your treatment and how to manage your condition.

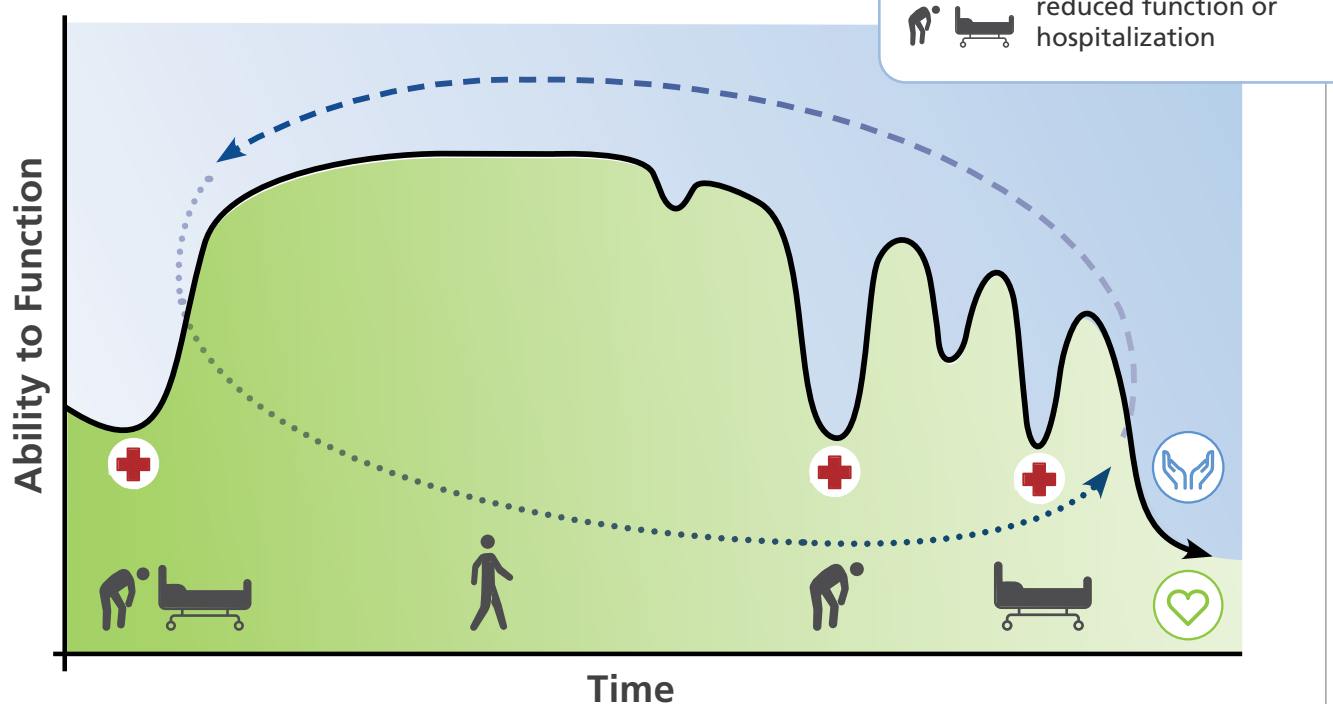
STAGE	Self-management and treatment options
<b>AT RISK FOR HEART FAILURE:</b> Heart failure has not developed yet. But you have several conditions that can lead to heart failure if not controlled (see <a href="#">page 6</a> ).	Managing or treating risk factors to prevent heart failure: <ul style="list-style-type: none"> <li>• Manage chronic conditions: high cholesterol, high blood pressure, and diabetes</li> <li>• Stop smoking, limit excess alcohol, and avoid illegal drugs</li> <li>• Exercise regularly and manage your weight</li> <li>• Know your family history of heart disease</li> </ul>
<b>PRE HEART FAILURE:</b> Your heart doesn't pump as much blood as you need, but you don't have symptoms. This also includes people with heart valve disease or a history of heart attack.	<ul style="list-style-type: none"> <li>• Managing risk factors (see above)</li> <li>• Taking medications to reduce further changes to the heart's function or structure." (see <a href="#">page 14</a>)</li> <li>• Managing any heart rhythm problems with an implantable device to control your heart rhythm</li> </ul>
<b>HEART FAILURE SYMPTOMS: (past or present)</b> Symptoms such as fatigue and feeling short of breath can occur when you are active.	<ul style="list-style-type: none"> <li>• Continuing the treatment used during the first 2 stages</li> <li>• Taking more medications to manage symptoms and help the heart (see <a href="#">page 14</a>)</li> </ul>
<b>ADVANCED HEART FAILURE:</b> At this stage, heart failure symptoms can be severe and they happen even while you are at rest. Medication doesn't manage symptoms well.	<ul style="list-style-type: none"> <li>• Continuing the treatments used during the first 3 stages</li> <li>• Mechanical devices to aid the heart</li> <li>• Heart transplant</li> <li>• Home care, palliative care, or hospice</li> </ul>

While it can seem discouraging to consider these stages, realize that they tell only part of the story. The rest of the story is yours to create. **By following MAWDS and working with your healthcare providers, you have the power to manage your symptoms and live well with heart failure.**

## YOUR HEART FAILURE JOURNEY

Your heart failure journey is as unique as your own experiences in life. The highs and lows will be determined by your treatment and lifestyle choices, and the nature of the disease. The graph below illustrates a general path towards maintaining health and when decisions need to be made regarding palliative and end-of-life care.

Along your journey, your medical and supportive care teams may be there to help as needed. The lists below show how they—and you—will influence your journey.



### Heart Failure Care (medical team)

- Determine diagnosis
- Set treatment plan
- Adjust medications as needed
- Monitor progress
- Discuss and perform advanced treatment options (procedures and surgeries)
- Provide guidance and referrals



### Supportive Care (patient, family, and care team)

- Set daily disease management tasks
- Address quality of life issues
- Discuss options for advanced heart failure treatment
- Identify my preferences for care
- Consult with palliative care team
- Choose my healthcare agent
- Make critical decisions
- Complete and document advance care plan



## YOUR PALLIATIVE AND HOSPICE CARE TEAM

Members of your palliative or hospice care team may include one or more of the following:

- A specially-trained doctor
- Physician assistant
- Nurse practitioner
- Nurse case manager
- Social worker
- Chaplain
- Nurse or nurse assistant

These professionals are as much a part of your care as your heart failure team.

## Advanced heart failure

Heart failure is a terminal illness. Short of heart transplant, it has no cure. It is progressive (gets worse over time) and will eventually bring about the end of life, despite best medical efforts. Often, people have many years of good quality of life. However, you can't control when you die. This is why it is important to think about and prepare for what the future may hold.

## Advance care planning (ACP)

An important part of heart failure treatment is shared decision making. This means having important discussions with your healthcare team about your condition and deciding on the best treatment options. This process of preparing for the future is called **advance care planning**.

ACP is a process to help you:

- Understand your illness situation and where it's heading
- Understand your options now and in the future
- Express your values and voice your preferences
- Receive guidance on communicating values and preferences with others
- Formally name and empower others to make medical decisions for you if you become too sick or sleepy to make those decisions yourself

ACP doesn't always make the hard decisions any easier, but it can make them more straightforward, and it can greatly comfort loved ones who, at some point, may need to make decisions for you. Good ACP improves your quality of life.

### What decisions might I need to make about my care?

As you approach advanced heart failure, you may need to make these kinds of decisions:

- How do I see myself eventually dying? Where would I want it to happen? When would it be okay for it to happen? What do I think I will die from?
- What makes me feel like I am "living" life as opposed to merely existing?
- Assuming I can still be comfortable: at what point should I stop going to the hospital for care to prolong my life? When would I stop out-of-hospital therapies to prolong my life?
- How do I feel about depending on family or friends to care for me? What do I expect them to do to prolong my life? How do I feel about living in a nursing home? How do I feel about paying for a nursing home?



# Palliative care and hospice care: What you should know

Both **palliative** [PAL-lee-uh-tive] **care** and **hospice** [HOSS-pis] **care** provide comfort when you have a serious illness. Palliative care often begins with your diagnosis. Care is provided at the same time as your other treatments. Hospice care usually begins when it is clear that you are nearing the end of life and have stopped treatment for your disease.

## Palliative care

The goal of palliative care is to help you feel better during treatment. It can help prevent or treat the symptoms and side effects from heart failure and its treatments. It can also help you manage the emotional, social, practical, and spiritual problems that heart failure can bring up. In short, it can help improve your quality of life.

Palliative care can be given at any stage of illness. Services are covered by most insurance companies. It can be provided in your home or a hospital or clinic. Some examples of palliative care services are:

- Managing symptoms, such as breathlessness, anxiety, or fatigue
- Completing important medical legal documents
- Helping you and your family make difficult care decisions
- Connecting you and your family with support services
- Counseling
- Emotional and spiritual support

## Hospice care

Hospice care provides comfort and support to you and your family as you are nearing the end of life. Hospice services are usually provided in the home by a team of medical professionals. They work together to create a care plan that is specific to your goals and needs. Your hospice care team may:

- Manage your medications
- Pay for and set up medical equipment
- Provide a break for family caregivers when needed
- Organize emotional and spiritual support
- Arrange for specialty therapies (art, music, etc.)
- Provide trained volunteers to run errands, prepare meals, etc.

Your care team will review your case from time to time to ensure that you continue to qualify for hospice services. Hospice services are typically covered at 100% by most insurance companies. This means that most people will not get a bill for these services.



These questions may seem overwhelming, but they don't have to be. Ask your care team for a copy of **Intermountain's Heart Failure Decision Aid** to help you and your family with these important discussions.

ADVANCE CARE PLANNING					
Heart Failure Decision Aid					
When heart failure (HF) progresses to an advanced stage, difficult decisions must be made. Making informed decisions requires teamwork through shared decision-making. This guide is designed to help you and your doctor align your health as it is now with what you determine to be your ideals, goals and priorities of care.					
Current situation	Your health now	Your goals, goals, and priorities	Your health now	Your goals, goals, and priorities	Your health now
Things to consider	<ul style="list-style-type: none"> <li>Your breathing and swelling problems may or may not be managed</li> <li>Symptoms, such as fatigue and feeling short of breath, may or may not be managed</li> <li>Some decisions may be made for you</li> </ul>	<ul style="list-style-type: none"> <li>You want the chance to live longer but DO NOT want invasive treatment support</li> <li>What you may experience</li> <li>Some decisions may be made for you</li> <li>Some decisions may be made for you</li> </ul>	<ul style="list-style-type: none"> <li>Your breathing and swelling problems may or may not be managed</li> <li>Activity is less tolerated</li> <li>What you may experience</li> <li>Some decisions may be made for you</li> <li>Some decisions may be made for you</li> </ul>	<ul style="list-style-type: none"> <li>You wish to live longer and will consider invasive treatment</li> <li>What you may experience</li> <li>Some decisions may be made for you</li> <li>Some decisions may be made for you</li> </ul>	<ul style="list-style-type: none"> <li>Ability to carry on as you are now</li> <li>Ability to carry on as you are now</li> <li>Ability to carry on as you are now</li> <li>Ability to carry on as you are now</li> </ul>
Options:	Non-Invasive Treatment/Support	Invasive Treatment/Support	End-of-Life Care (care focused on giving you comfort)	End-of-Life Care (care focused on giving you comfort)	End-of-Life Care (care focused on giving you comfort)
Devices used	<p>Manage risk factors: high cholesterol, high blood pressure, diabetes</p> <p>Manage lifestyle: stop smoking, limit exercise, avoid alcohol, avoid drugs, and a low-fat/low-sodium diet, be active</p> <p>Take medications as prescribed:</p> <ul style="list-style-type: none"> <li>ACE inhibitors (Lisinopril, Capoten, Ramapril, Benazepril, Vasotec, Fortovase)</li> <li>ARBs (Losartan, Valsartan, Telmisartan, Candesartan, Valsartan, Canesartan)</li> <li>Beta Blockers (Bisoprolol, Carvedilol, Atenolol, Timolol, etc.)</li> <li>Diuretics (Furosemide, Torsemide, Bumetanide)</li> <li>Alcohol/Beta Blocker (Propranolol, Eplerenone)</li> </ul>	<p>TAVR (Transcatheter Aortic Valve Replacement): A procedure that treats aortic valve that isn't working properly because it has become thick or stiff. During the TAVR, the doctor uses a catheter to place the new valve into your chest.</p> <p>Aortic Valve Replacement Open Heart Surgery: This is an open heart surgery to replace the aortic valve. This is a major surgery that requires a large team of doctors and nurses.</p> <p>Resuscitation: Resuscitation is a procedure that is used to restart the heart and breathing. It is used when the heart and breathing have stopped.</p> <p>ICD (Implanted Cardioverter Defibrillator): An ICD does everything a pacemaker does, however, it also has a defibrillator attached that can deliver a shock to the heart if it senses a dangerous rhythm, such as those that cause sudden cardiac arrest.</p>	<p>Options for shortness of breath:</p> <ul style="list-style-type: none"> <li>Medication to help you relax and for anxiety or pain relief</li> <li>Physical aide to help with comfort (e.g., adjustable bed, nursing care in your home)</li> <li>Emotional support (e.g., social work, chaplain, etc.) for you and your loved ones</li> </ul>	<p>Options for shortness of breath:</p> <ul style="list-style-type: none"> <li>Medication to help you relax and for anxiety or pain relief</li> <li>Physical aide to help with comfort (e.g., adjustable bed, nursing care in your home)</li> <li>Emotional support (e.g., social work, chaplain, etc.) for you and your loved ones</li> </ul>	<p>Options for shortness of breath:</p> <ul style="list-style-type: none"> <li>Medication to help you relax and for anxiety or pain relief</li> <li>Physical aide to help with comfort (e.g., adjustable bed, nursing care in your home)</li> <li>Emotional support (e.g., social work, chaplain, etc.) for you and your loved ones</li> </ul>



# Heart Failure Action Plan

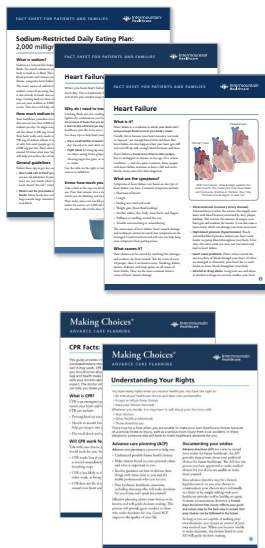
To help you monitor your condition — and prevent a bad situation from becoming worse — use this Heart Failure Action Plan. Your Action Plan divides your symptoms into three zones. Use your Intermountain MAWDS Heart Failure Self-Care Diary to record your zones every day.

<ul style="list-style-type: none"> <li>• Feeling well</li> <li>• Breathing is easy</li> <li>• Weight is stable</li> <li>• Symptoms are stable</li> </ul>	 <p><b>GO</b></p> <p><i>maintain therapy</i></p>	<p><b>Keep up the good work!</b></p> <p><b>Follow MAWDS every day!</b></p>
<ul style="list-style-type: none"> <li>• Not feeling well</li> <li>• If you gain more than 2 or 3 pounds in one day or are 5 pounds over your target weight</li> <li>• Noticeable swelling or bloating</li> <li>• Some difficulty breathing with activity and at night</li> <li>• Symptoms are worsening</li> </ul>	 <p><b>CAUTION</b></p> <p><i>step up therapy</i></p>	<p><b>Call your healthcare provider to find out how to prevent symptoms from becoming severe.</b></p> <p>Provider's instructions:</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>
<ul style="list-style-type: none"> <li>• Breathlessness or chest heaviness at rest</li> <li>• Weight is up more than 5 pounds in one day</li> <li>• Fainting</li> <li>• Symptoms are severe</li> </ul>	 <p><b>STOP</b></p> <p><i>get help now</i></p>	<p><b>Call your healthcare provider or go directly to the emergency room. DO NOT try to treat this yourself.</b></p> <p>Provider's number: _____</p> <p>Emergency number: <b>911</b></p>

## Helpful information

These resources provide information, encouragement, and support:

- **Heart Failure fact sheet**  
Information on symptoms, diagnosis, treatment options, and lifestyle management
- **Heart Failure: Tracking your fluids fact sheet**  
A tool to track your fluid intake
- **Sodium-Restricted Daily Eating Plan fact sheet**  
A tool to track your sodium intake
- **CPR Facts: What you should know fact sheet**  
A tool to help you understand what CPR is and when it is beneficial
- **Advance Care Planning: Understanding Your Rights fact sheet**  
Helps you understand your rights when considering advanced care



## Internet sites

- **Intermountain Healthcare**  
Heart Failure Education: [intermountainhealthcare.org/health-information/health-library/patient-handouts](https://intermountainhealthcare.org/health-information/health-library/patient-handouts)  
(type “heart failure” in the search field)  
Advance Directive: [intermountainhealthcare.org/health-information/advance-directive](https://intermountainhealthcare.org/health-information/advance-directive)
- **Cardiosmart—American College of Cardiology:**  
[cardiosmart.org/topics/heart-failure/living-with-heart-failure](https://cardiosmart.org/topics/heart-failure/living-with-heart-failure)
- **American Heart Association:** [heart.org](https://heart.org)
- **Heart Failure Society of America:** [abouthf.org](https://abouthf.org)
- **American Association of Heart Failure Nurses (AAHFN):**  
[aahfn.org/mpage/patiented](https://aahfn.org/mpage/patiented)
- **National Heart, Lung, and Blood Institute:**  
[nhlbi.nih.gov/healthtopics/heart-failure](https://nhlbi.nih.gov/healthtopics/heart-failure)

## Books

- **Congestive Heart Failure: Understanding your heart disease — Simple and Compact** by Robert S. Harris.
- **Success with Heart Failure Revised: Help and Hope for Those with Congestive Heart Failure** by Marc Silver
- **500 15-Minute Low Sodium Recipes: Fast and Flavorful Low-Salt Recipes that Save You Time, Keep You on Track, and Taste Delicious** by Dick Logue



## REACH OUT FOR SUPPORT!

Self-management is critical to your health, so it's important to get support in following your care plan. Support can also help you understand and manage your reactions to your diagnosis so they don't get in the way of what you need to do.

If you need encouragement, advice, or just someone to talk to, reach out to family members and your heart care team. Also, take advantage of the resources listed on this page.

To find this booklet and other patient education, go to:  
[intermountainhealthcare.org/heartfailure](https://intermountainhealthcare.org/heartfailure)



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