

# Living with Heart Failure

A GUIDE FOR PATIENTS AND CARE PARTNERS



THE DRIVE IS *here.*<sup>®</sup>

[BAYHEALTH.ORG/CARDIOVASCULAR](http://BAYHEALTH.ORG/CARDIOVASCULAR)



*Dear Patient,*

Thank you for allowing the doctors, nurses and other staff at Bayhealth to partner with you to meet your healthcare needs. Having been told you have heart failure, you may be concerned about what to expect and have many questions.

This guide will go over important information for you and your care partner and will serve as a resource during your hospital stay and when you go home. Following the guidelines for care and lifestyle modifications will allow you to successfully manage your condition and live well with heart failure. If you have any questions, please don't hesitate to contact us at \_\_\_\_\_.

Sincerely,

*Your Bayhealth Care Team*



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# Personal Health Information for:

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PATIENT NAME

*I should eat less than \_\_\_\_\_ grams or \_\_\_\_\_ milligrams of sodium per day. See pages 6 and 7 for details.*

*My fluid intake should be less than \_\_\_\_\_ cups per day. All foods that melt at room temperature need to be counted as fluid. See page 8 for details.*

## SELF-CARE CHECKLIST

- I know my blood pressure
- I will weigh myself every day (and will tell someone if I don't have a scale at home)
- I will schedule and go to all follow-up appointments (and will tell someone if I need transportation)
- I know when to call my doctor for worsening symptoms
- I have an advance healthcare directive

## IMPORTANT NAMES AND PHONE NUMBERS

My primary care provider:

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NAME PHONE NUMBER

My cardiologist:

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NAME PHONE NUMBER

My pharmacy:

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NAME PHONE NUMBER

My home healthcare agency:

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NAME PHONE NUMBER

My oxygen supplier:

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NAME PHONE NUMBER

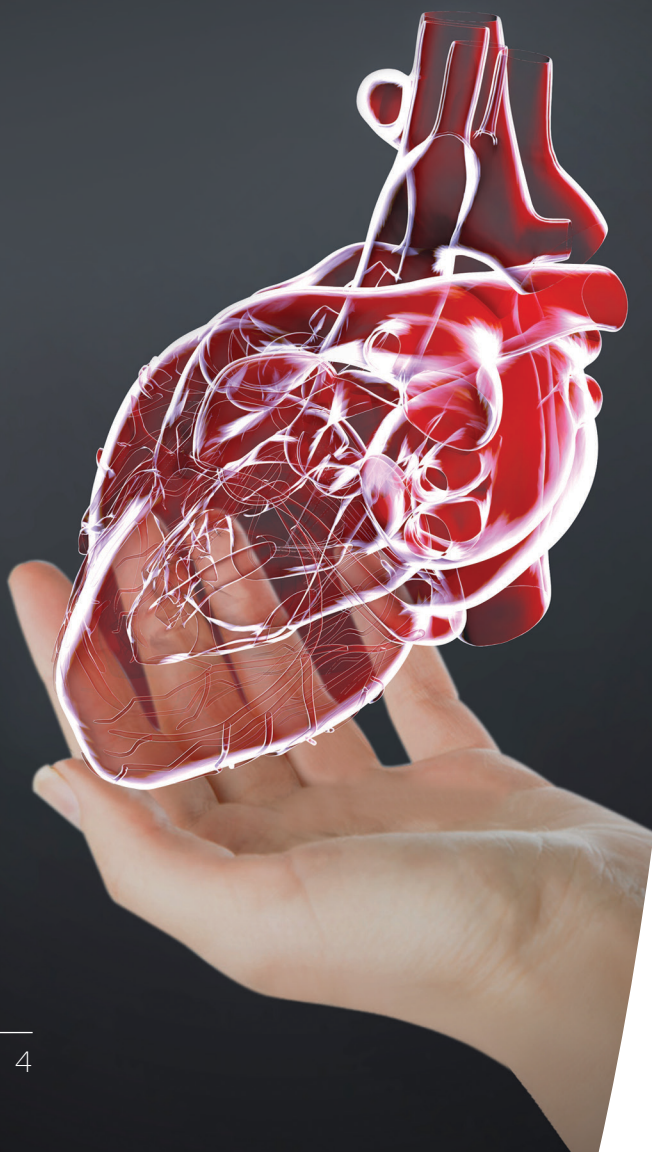
Emergency contact:

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NAME PHONE NUMBER

## The Heart

Our heart pumps about 6 gallons of blood a minute to all organs and tissues. The heart muscle determines how fast or how slow to pump in order to meet the needs of our body. Our blood carries oxygen and other important elements to all tissues and returns the blood to our lungs, kidneys and liver in order to clean, filter and pick up more oxygen. The cycle repeats itself effortlessly every minute of the day. Our healthy heart is about the size of our fist and weighs about 9 ounces in the female and 11 ounces in the male.



## CHAMBERS OF THE HEART

The heart has two top chambers called atria and two bottom chambers called ventricles. Our heart has a right side with the right atrium and right ventricle, and a left side with the left atrium and left ventricle. The tricuspid valve is between the right atrium and right ventricle. The mitral valve is between the left atrium and left ventricle. The pulmonary valve is the gatekeeper to the lungs, and the aortic valve is the gatekeeper to the largest blood vessel in our body.

The valves in our heart keep blood going in one direction. Our heart has a working phase called systole (sis-toe-lee) and a resting phase called diastole (die-as-toe-lee). During the resting phase, our heart feeds the arteries in the heart called coronary arteries.

## OUR ELECTRICAL SPARK

Our heart's pumping system needs the electrical spark in order to work. This is known as the conduction system. These special cells are in our atria and ventricles. The healthy heart pumps between 60 to 100 times a minute.

## What is Heart Failure and How is it Treated?

When your heart muscle is weakened, you can develop a condition called heart failure. The sick heart can become too large and not pump well, or become stiff despite normal size on the outside because the inside of the heart chambers have become very thick, reducing the space for blood. One chamber or all chambers of the heart can be affected. A stretched or stiff heart muscle is weakened and does not pump as well as it should. Your doctor will tell you what type of heart failure you have.

Heart failure affects millions of people, and thousands of new heart failure patients are being diagnosed each year. There is no cure for heart failure, but it can be controlled. Treatment for heart failure is improving all the time. It is important for you to understand your type of heart failure and treatment plan. You and your doctor are partners in keeping you feeling well and enjoying life for as long as possible.

### Common causes of heart failure:

- High blood pressure
- Heart attack
- Heart valve problems
- Irregular heartbeat (e.g. atrial fibrillation)
- Infection

## Symptoms you should report

*(can be mild or very limiting):*

- Shortness of breath
- Swelling of the ankles/legs/abdomen
- Sudden weight gain
- Increased tiredness
- Cough, especially at night
- Unable to lie down; need “extra” pillow
- Change in appetite or feeling full

## Heart failure treatments:

- Medicine
- Exercise — ask your doctor if you qualify for cardiac rehabilitation
- Surgery
- Medical devices
  - Wearable cardioverter defibrillator (LifeVest®)
  - Implantable cardiac defibrillator
  - Permanent pacemaker
  - Left ventricular assist device (LVAD)
- Weight reduction
- Oxygen therapy
- Lifestyle changes
  - Diet
  - Stop smoking
  - Avoid alcohol
  - Reduce stress

## What to Expect in the Hospital

A heart failure diagnosis and initial treatment may require a hospital stay of a few days or more, depending on your needs. If you are hospitalized, your healthcare team will provide immediate care and begin working with you and your care partners on a plan to help you manage your heart failure upon discharge.

### During your hospital stay, you can expect the following:

- You will be weighed daily (every morning)
- You may be seen by a cardiologist
- You will be put on a low-sodium diet
- Your urine output will be measured daily
- Your fluid intake will be monitored and you may be put on a fluid restriction
- You may get a visit from a Palliative Care team member to talk about goals of care

## Managing Your Heart Failure: Guidelines & Daily Living

Continuing your treatment plan at home and maintaining healthy habits in daily life are essential to managing your heart failure. You will likely need to make some lifestyle modifications, including diet and activities. It is also important to take your prescribed medications and follow the various guidelines to keep your condition in check. We've listed plenty of tips to help you. Be sure to pay attention to your body's signals and contact your doctor right away if you experience changes in your condition or any new symptoms.

### STAYING IN THE ZONE

The best way to be sure that you are on target each day is to look at the guidelines under the Self-Check Plan on page 11.

Your goal is to stay in the Green Zone. When you experience any of the symptoms under the Orange Zone, you should contact your doctor. If you are struggling to breathe, have chest pain, or become confused and are unable to think clearly, you are in the Red Zone. If any of these symptoms occur, you need to call 911 or go to the nearest emergency department.

### Healthy dos and don'ts:

- Weigh yourself every day — in the morning after you have gone to the bathroom and urinated, without clothes and on the same scale
- Take your medicine as directed
- Monitor your blood pressure regularly — your doctor will tell you the recommended range for your blood pressure
- Follow your diet and fluid restrictions
- Regular activity — balance rest/activity
- Keep your doctor appointments
- Do not smoke — if you need help quitting, speak to your doctor
- Limit intake of alcoholic beverages

### WHEN TO CONTACT YOUR DOCTOR

In addition to following the Self-Check Plan, being on the lookout and identifying any new or worsening symptoms is very important to the ongoing management of your condition. There are a number of warning signs that you should report to your doctor.

### Warning signs and symptoms to report:

- Chest pain
- Increase in shortness of breath
- I have to use more than the average amount of pillows to sleep
- My socks are leaving marks on my legs
- My shoes are feeling tight
- I have gained more than two to three pounds in a day, or five pounds in a week
- I have new symptoms, such as waking up at night or feeling short of breath

### ACTIVITY GUIDELINES

Staying physically active is beneficial for everyone, including those with heart failure. Ask your doctor about what types and amount of activity are right for you. You may be a candidate for cardiac rehabilitation, a medically supervised program of exercise and education to help patients with heart failure improve their cardiovascular health.

#### Tips for resuming physical activity:

- Start slow
- Avoid hot or cold temperatures
- Wait 1-2 hours after meals to perform activities
- Report any changes in activity tolerance

### PREVENTION TIPS

Unfortunately, heart failure may make you more likely to get pneumonia and other illnesses. Getting good rest will help, and there are some things you can do to reduce the risk.

#### Tips to avoid illness:

- Check with your doctor to see if you are a candidate for flu or pneumonia shots
- Stay away from people who are ill or who have respiratory infections
- Avoid large crowds

### The following will help ensure you get plenty of rest:

- Plan at least one short nap (under an hour) every day; longer naps may make it difficult to sleep at night
- Avoid working long days
- Rest between periods of heavy activity — alternate light and heavy activities
- When you rest, elevate your legs to help keep the swelling down
- If your doctor has prescribed oxygen therapy, or devices such as bilevel positive airway pressure (BiPAP) or continuous positive airway pressure (CPAP), use as directed



### YOUR DIET

A low-sodium diet helps to control heart failure symptoms and prevent other problems. Sodium is a mineral found in many foods, particularly salt. Ask your doctor how much sodium you can have. You may be limited to 2 to 4 grams (2000 mg or 4000 mg or 1–2 teaspoons) each day. It is important to read food labels for sodium content.

Take the salt shaker off the table. Season your foods with flavorings such as pepper, lemon, garlic, and onion instead of salt. Do not use salt substitutes without asking your doctor.

**Limit these ingredients in your diet:**

- Salt
- Monosodium glutamate (MSG)
- Baking soda
- Baking powder
- Disodium phosphate (additive to preserve foods, may be found in cereals and milk)
- Anything that has the word “sodium” in it

**Limit these high-sodium foods in your diet:**

- Bacon, ham, corned beef, hot dogs, sausages, and luncheon meats
- Most cheeses
- Canned soups and vegetables (that do not say “low-sodium”)
- Tuna, sardines or shellfish that are canned in oil
- Frozen dinners with more than 700 mg of sodium per serving
- Potato chips, pretzels and crackers
- Ketchup, mayonnaise, sauces and salad dressings
- Most fast foods
- Pickles and olives

**Include foods that have little or no added salt:**

- Fresh foods, including vegetables and fruits
- Lean meats
- Frozen vegetables without sauce
- Products that say “low-sodium” or “no sodium” on the label

You and your care partner may need to see a dietitian for special diet instructions and meal planning. They can also teach you how to read food labels for sodium content. Changing your diet can be hard. Eating less sodium in your diet may not be easy at first, but you will adjust. If you have trouble changing your diet, ask a member of the healthcare team for help.

**Eating out on a low-sodium diet**

Choose a restaurant with a wide variety of menu items. Look for items naturally low in sodium or ask that your favorite dish be prepared without added salt. Ask that sauces and salad dressings be served on the side, so that you can control how much you use. Squeeze lemon on your salad instead of dressing. Stay away from fast foods like burgers, fries and pizza, which are very high in salt.

**Tips for eating out:**

- At Chinese/Japanese restaurants, request no soy sauce and no MSG.
- At Italian restaurants, ask for less sauce and cheese on your meal, or order a lunch-size portion. Go easy on the grated Parmesan cheese.



## FLUID CONTROL

Your doctor may recommend limiting your fluid intake to help you control your heart failure. If this is the case, you will need to monitor on a daily basis how much fluid you drink and any other liquids from foods that you consume.

### Measure and count the following as fluids:

- Coffee
- Cream
- Non-dairy creamer
- Milk
- Juice
- Punch
- Soda
- Soups
- Tea
- Water (including when taking pills)
- $\frac{1}{2}$  cup of gelatin, ice cream, sherbet or frozen yogurt =  $\frac{1}{2}$  cup fluid
- $\frac{1}{2}$  cup piece of watermelon =  $\frac{1}{2}$  cup fluid
- $\frac{1}{2}$  of a grapefruit =  $\frac{1}{2}$  cup fluid
- 1 medium orange =  $\frac{1}{2}$  cup fluid
- 1 double ice pop = 1 cup fluid
- Ice cubes (melt in a measuring cup to determine fluid content)

### Fluid equivalents

1 cup	= 8 fluid ounces	= 237 milliliters
$\frac{1}{2}$ cup	= 4 fluid ounces	= 118 milliliters
$\frac{1}{3}$ cup	= 2 $\frac{2}{3}$ fluid ounces	= 79 milliliters
2 Tablespoons	= 1 fluid ounces	= 30 milliliters

### The following may be helpful to relieve thirst:

- Chewing gum
- Sucking on sour candy
- Rinsing mouth with mouthwash
- Eating frozen grapes (limit to 15 per day)
- Avoiding salty foods – they make you thirsty

### Tips for measuring fluids during the day:

- Use plastic ice cubes — they do not add fluid to your beverages
- Use the “pitcher method” of measuring your fluid intake.
  - Fill pitcher of water to daily limit each morning
  - When you drink or eat any fluid, discard the same amount of water from the measuring pitcher
  - When taking pills, use the water from the measuring pitcher
  - Once pitcher is empty, do not drink any more fluid

## YOUR MEDICATIONS

Even if you are feeling better, take your medications as prescribed! Don't stop taking a medication without talking to your doctor first. Changing or skipping doses can be dangerous. Be sure to follow your discharge instructions or any changes in your prescribed medications.

### Tips for managing your medications:

- Ask questions about your medications if you don't understand what they are for.
- Check the label before you take a medication. Be sure you are taking the right one and have the correct dose. Always follow the directions carefully. If you have difficulty understanding any of your medications, discuss with your doctor or pharmacist.
- Don't take medications in the dark – it's easy to make a mistake and take the wrong one.
- Tell your doctor if you take any over-the-counter drugs. They could react with other medications that you have been prescribed.
- Ask your doctor what you should do if you miss a dose. Never take a larger dose the next time without checking with your doctor.
- Report new side effects of medication to your doctor. The doctor may adjust your dose, prescribe something different, or make other changes.

### Keeping track of your medications

It is important to always carry a list of medications with you. This list can help healthcare professionals treat you in an emergency.

Keep track of your medications by using a pill dispenser. Keeping a written record of your medications, including vitamins and over-the-counter drugs, will help you remember to take them on schedule. Please tell your doctor or nurse if you cannot afford your medications.



## HEART FAILURE AND INTIMACY

It is natural to wonder if you can continue to have an active sex life with heart failure. Ask your doctor when you can resume physical intimacy.

### Tips for resuming physical intimacy:

- Make sure you are rested and relaxed
- Avoid having sex after eating a heavy meal

### Stress and relaxation techniques

Stress makes the heart work harder, which can potentially lead to worsening symptoms of heart failure. Making relaxation a part of your routine may be helpful.

Deep breathing is the cornerstone of relaxation. It is easy to learn, can be practiced almost anywhere, and provides a quick way to get your stress levels in check. All you really need is a few minutes and some privacy.

### How to practice deep breathing:

The key to deep breathing is to breathe deeply from the abdomen, getting as much fresh air as possible in your lungs. When you take deep breaths from the abdomen, rather than shallow breaths from your upper chest, you inhale more oxygen. The more oxygen you get, the less

tense, short of breath and anxious you feel. The next time you feel stressed, take a minute to slow down and breathe deeply.

## DEPRESSION AND YOUR HEART

It is normal to feel uneasy, down or sad after being diagnosed with heart failure. These feelings may naturally result from concerns about living with this condition and making adjustments in your life going forward. There are many symptoms that often accompany changes in your mood. You should not be ashamed about seeking support to help you cope with your feelings. If these feelings persist even after you resume normal activities, or they worsen and start to interfere with your daily life, you may have depression. Just like high cholesterol, hypertension and obesity, depression is a risk factor in heart disease and it is important to let your doctor know.

### What can you do when you are depressed?

- Tell your doctor
- Exercise, if you can
- Contact someone in your social circle, church or other groups you may belong to
- Practice stress-reducing tips

## OXYGEN THERAPY

Oxygen therapy may be prescribed for you if you are having trouble breathing. The flow (how much oxygen) rate will be ordered. Never change the flow rate unless you call your doctor.

### Have the medical equipment supplier show you how to:

- Set up the oxygen cylinder
- Refill the tank (if necessary)
- Clean the equipment
- Check the flow rate

### Here are some important safety tips:

- No one can smoke near the equipment
- Keep oxygen tank at least 10 feet away from an open flame, gas or wood burning stove
- Keep oxygen tank 10 feet away from electrical appliances that may spark
- Do not put oxygen tubing under blankets, clothing, furniture or carpeting



## YOUR WEIGHT

Use the chart below to track your weight. Weigh yourself at the same time every day, preferably when you wake up in the morning and after urinating. Be sure to wear the same amount of clothing every time you weigh yourself, and use the same scale, when possible.

In the box under each day of the week, indicate your daily weight and in the shaded box next to it, mark whether this was a weight gain (+), weight loss (-) or if the weight stayed the same as the previous day (=).

WEEK OF	SUN	+/-	MON	+/-	TUE	+/-	WED	+/-	THUR	+/-	FRI	+/-	SAT	+/-

## SELF-CHECK PLAN FOR HEART FAILURE MANAGEMENT

Follow this chart from the American Heart Association to help you manage your heart failure and keep symptoms in check.



# Self-Check Plan for HF Management



### Excellent – Keep Up the Good Work!



No new or worsening shortness of breath



Physical activity level is normal for you



No new swelling, feet and legs look normal for you



Weight check stable  
Weight: \_\_\_\_\_



No sign of chest pain

**GREAT!  
CONTINUE:**



Daily Weight Check



Meds as Directed



Low Sodium Eating



Follow-up Visits



### Pay Attention – Use Caution!



Dry, hacking cough



Worsening shortness of breath with activity



Increased swelling of legs, feet, and ankles



Sudden weight gain of more than 2-3 lbs in a 24 hour period (or 5 lbs in a week)



Discomfort or swelling in the abdomen



Trouble Sleeping

**CHECK IN!**

Your symptoms may indicate:



A need to contact your doctor or provider



A need for a change in medications



### Medical Alert – Warning!



Frequent dry, hacking cough



Shortness of breath at rest



Increased discomfort or swelling in the lower body



Sudden weight gain of more than 2-3 lbs in a 24 hour period (or 5 lbs in a week)



New or worsening dizziness, confusion, sadness or depression



Loss of appetite



Increased trouble sleeping; cannot lie flat

**WARNING!** You need to be evaluated right away.



Call your physician or call **911**



[www.RiseAboveHF.org](http://www.RiseAboveHF.org)

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# Notes

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## Useful Resources

**American Heart Association**  
Heart.org

*This is the nation's oldest and largest voluntary organization dedicated to fighting heart disease and stroke. It funds research and promotes advocacy and also provides web-based tools and information for those living with heart failure and their families, including free newsletters.*

**Delaware Medicaid & Medicare**  
Toll Free Help Line: 1-800-464-HELP (4357)

*There are many websites and free online resources such as apps to assist with health management. These may be beneficial tools to help you monitor activities and better manage your heart failure and overall health.*

**Bayhealth PACE (Promoting Active Community Engagement) Program**  
Bayhealth.org/PACE

*This free program is for anyone in Bayhealth's service area who is interested in living a healthier life. PACE Clinics, which are held monthly in Dover, Lincoln and Milford, give you an opportunity to receive individualized counseling from a registered nurse (RN) based on your health problems, medications and blood pressure. Quarterly lectures will also be provided.*

**Delaware Quitline**  
Quitnow.net/delaware  
Toll Free: 1-866-409-1858



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