Heart Failure:
A Guide for Patients, Families and Caregivers

This patient information booklet was produced by the Hartford HealthCare Congestive Heart Failure Team.
Contact Information:

Cardiologist: ________________________________
Number: ________________________________

Primary Care Provider*: ________________________________
Number: ________________________________

Additional Provider*: ________________________________
Number: ________________________________

Homecare Agency: ________________________________
Number: ________________________________

Pharmacy: ________________________________

*A provider can be a doctor, a nurse practitioner (advanced practice registered nurse, APRN) or a physician assistant (PA).
What is Heart Failure?

Heart failure is a lifelong condition that may not go away. But you **CAN** live with it:

- Heart failure means that your heart is not pumping blood as well as it should.
- IT DOES NOT MEAN your heart is no longer working or is going to stop.
- When the heart doesn't pump as well as it should, blood can back up in your lungs and other parts of your body.

**Sometimes heart failure is called:**

- “Water in the lungs”
- Congestive heart failure (CHF)
- Pulmonary edema
## Warning Signs of Heart Failure

<table>
<thead>
<tr>
<th>Sign or symptom</th>
<th>People may experience</th>
<th>Why it happens</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shortness of breath</td>
<td>Breathlessness during activity (most common), at rest or while sleeping, which may come on suddenly and wake you up. You often have difficulty breathing while lying flat and may need to prop up the upper body and head on two pillows. You often complain of waking up tired or feeling anxious and restless.</td>
<td>Blood backs up in the pulmonary veins (the vessels that return blood from the lungs to the heart) because the heart can't keep up with the supply. This causes fluid to leak into the lungs.</td>
</tr>
<tr>
<td>Persistent coughing or wheezing</td>
<td>Coughing that produces white or pink blood-tinged mucus.</td>
<td>Fluid builds up in the lungs (see above).</td>
</tr>
<tr>
<td>Buildup of excess fluid in body tissues (edema)</td>
<td>Swelling in the feet, ankles, legs or abdomen or weight gain. You may find that your shoes feel tight.</td>
<td>As blood flow out of the heart slows, blood returning to the heart through the veins backs up, causing fluid to build up in the tissues. The kidneys are less able to dispose of sodium and water, also causing fluid retention in the tissues.</td>
</tr>
<tr>
<td>Tiredness, fatigue</td>
<td>A tired feeling all the time and difficulty with everyday activities, such as shopping, climbing stairs, carrying groceries or walking.</td>
<td>The heart can't pump enough blood to meet the needs of body tissues. The body diverts blood away from less-vital organs, particularly muscles in the limbs, and sends it to the heart and brain.</td>
</tr>
<tr>
<td>Lack of appetite, nausea</td>
<td>A feeling of being full or sick to your stomach.</td>
<td>The digestive system receives less blood, causing problems with digestion.</td>
</tr>
<tr>
<td>Confusion, impaired thinking</td>
<td>Memory loss and feelings of disorientation. A caregiver or relative may notice this first.</td>
<td>Changing levels of certain substances in the blood, such as sodium, can cause confusion.</td>
</tr>
<tr>
<td>Increased heart rate</td>
<td>Heart palpitations, which feel as if your heart is racing or throbbing.</td>
<td>To make up for the loss in pumping capacity, the heart beats faster.</td>
</tr>
</tbody>
</table>

*American Heart Association*
Living Well

Many people lead full, enjoyable lives by managing their heart failure.

Heart failure can be managed with:

- Daily use of the “What Color Am I Today” chart (page 4)
- Weighing yourself daily
- Medications
- Eating a healthy diet
- Exercise
- Close communication with your provider and loved ones
- Limiting alcohol and caffeine
- Not using tobacco products
- Various procedures
- Surgery

“Just ask”

- What is the right treatment for me?
- Are home nursing visits right for me?
What Color Am I Today?

GREEN ZONE
“All Clear”- GOAL
• No shortness of breath – breathing easily
• No weight gain of more than 3 pounds per day
• No swelling of feet, ankles, legs or stomach/belly
• No chest pain

What to do:
• Keep up the good work!!
• Take your medicine
• Eat a low-salt diet
• Weigh yourself every day

YELLOW ZONE
TAKE ACTION!
• Weight gain of 3 pounds in one day or 5 pounds in one week
• More shortness of breath – breathing harder
• Harder to breathe lying down
  » Using more pillows
  » Sleeping in a chair
• More swelling in your feet, ankles, legs or stomach/belly
• Feeling more tired
• New or unusual coughing
• Dizziness

What to do:
• Call your provider:
  Name____________________
  Number__________________
• Home Health Agency
  Name____________________
  Number__________________

RED ZONE
“EMERGENCY”
• Struggling to breathe even when resting
• Chest pain or discomfort
• Fainting
• Confusion

What to do:
• Call 911 or
• Get help and go to the emergency room
Weigh Yourself Daily

Weight gain from water can start up to two weeks before you feel any symptoms.

Things you need to do:

- Weigh yourself EVERY DAY and write it down.
  - Around the same time
  - After urinating
  - Before having anything to eat or drink
  - Wearing the same amount of clothing
  - Using the same scale

Call your provider if you gain 3 pounds in one day or 5 pounds in one week.

- Bring the weight chart to all appointments.

“Just Ask”

- What is my target weight?
Medication Tips

- Bring all your medication BOTTLES to every appointment, including all the over-the-counter and herbal medications you take.
- Have an UPDATED list of your medications with you at all times. Medications can change often.
- Use a pill box to keep track of when to take your medications.
- Try to buy all of your medications from one pharmacy. This will allow the pharmacist to check for medication problems.
- DO NOT STOP taking your medications without speaking with your provider first.
- DO NOT take a double dose of medication if you miss a dose.

“Just Ask”

- What do I do if I miss a dose of medication?
- Is my pharmacy able to fill my pill box?
- Do I have any medication changes?
  » If the answer is yes, ask the pharmacist to write down the changes for you.
- Are there any medication side effects I should know about?
- Are herbal remedies, vitamins, supplements or teas safe to take with my prescribed medications?
- Can I take all my medications together?
Angiotensin-converting-enzyme inhibitors (ACE Inhibitors) or Angiotensin II receptor blockers (ARB)

These medications lower your blood pressure and make it easier for your heart to pump blood.

These medications include:
- losartan/Cozaar
- valsartan/Diovan
- irbesartan/Avapro
- candesartan/Atacan
- telmisartan/Micardis
- lisinopril/Zestril
- enalapril/Vasotec
- ramipril/Altace

Side effects and special instructions:

- At first, this medicine may cause mild weakness or dizziness. This should go away as your body gets used to the medication. If the dizziness is very bad, call your provider right away.

- Sometimes, ACE/ARB Inhibitors can cause a harmless dry cough. Speak with your provider if this happens.

- ACE/ARB Inhibitors can affect the potassium in your body. Your provider will check your potassium regularly.

- Speak with your provider before you take medicines such as Advil, Motrin, Aleve, ibuprofen, or naproxen. These can affect how your ACE/ARB Inhibitor works.

The ACE/ARB that I take is: ____________________________________________________________

Date: ____________________
Beta Blockers

Beta blockers lower your heart rate and make it easier for your heart to pump blood.

**Side effects and special instructions:**

- When starting this medication, you may experience weakness or dizziness. This should go away as your body gets used to the medication.

- Take this medicine with food.

- You may have fewer side effects if you take this medication at a different time from your other medications.

- This medication can hide the symptoms of low blood sugar in diabetic patients. Diabetics should check blood sugars regularly.

The Beta blocker that I take is: __________________________________________________________

Date: __________________________
Diuretics (Water Pills)

Diuretics remove extra water that builds up in your body and cause you to urinate more often. This will make it easier for your heart to pump.

**Side effects and special instructions:**

- Weigh yourself every day so your provider can prescribe the best dose for you.
- Some diuretics remove potassium from your body while others help you hold onto potassium. Your provider will be checking your potassium regularly.
- You may be more comfortable if you take this medication in the morning so that your sleep will not be interrupted by trips to the bathroom.

The diuretic that I take is: __________________________________________________________

Date: ________________

Potassium Supplements

Potassium is important to keep your heart pumping regularly. If it is too low or too high, your heartbeat can become dangerous.

**Side effects and special instructions:**

- Your provider will check your potassium regularly.
- If you have new muscle cramping or severe muscle weakness, do not stop taking your medications but CALL YOUR PROVIDER.

The potassium supplement that I take is: __________________________________________________________

Date: ________________

These medications include

- hydrochlorothiazide/Hydro-DIURIL
- chlorothiazide/Diuril
- furosemide/Lasix
- metolazone/Zaroxolyn
- torsemide/Demedex
- bumetanide/Bumex

These medications include

- Potassium chloride ER
- Klor-Con
- K-Tab
- Klor-Con
Tips for Eating Healthy

Salt is also called “SODIUM” and is found in most of the foods you eat.

If it says “salt,” it IS salt.
For example: sea salt, kosher salt, celery salt, onion salt, garlic salt

Why do you need to avoid salt in your diet?

• Salt/sodium acts like a sponge and makes your body hold onto water.
• That extra water can cause weight gain, swelling and problems breathing.

How much sodium can you have each day?

• Less than 1500 mg of sodium each day.

• <1500 mg daily of sodium


Reading a Nutrition Label

First, check the serving size. If you double the serving size, then you have to double the sodium.

<table>
<thead>
<tr>
<th>Nutrition Facts</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Serving Size</strong></td>
</tr>
<tr>
<td><strong>Servings Per Container</strong></td>
</tr>
</tbody>
</table>

**Amount Per Serving**

<table>
<thead>
<tr>
<th>Calories</th>
<th>170</th>
<th>Calories from Fat</th>
<th>130</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>%Daily Value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Fat</td>
</tr>
<tr>
<td>Saturated Fat</td>
</tr>
<tr>
<td>Trans Fat</td>
</tr>
<tr>
<td>Cholesterol</td>
</tr>
<tr>
<td><strong>Sodium</strong></td>
</tr>
<tr>
<td>Total Carbohydrate</td>
</tr>
<tr>
<td>Dietary Fiber</td>
</tr>
<tr>
<td>Sugar</td>
</tr>
<tr>
<td>Protein</td>
</tr>
</tbody>
</table>

A 0% * Vitamin C 0%
Calcium 0% * Iron 20%

Percent daily values are based on a 2000 calorie diet. Your daily values may be higher or lower depending on your calorie needs:

Calories per Gram

Fat 9 * Carbohydrate 4 * Protein 4

Look at the % of sodium on the label. Choose foods with 5% or less.

Keep track of the milligrams per serving to make sure you eat less than 1500 mg of sodium per day.

Key Words To Know

“Sodium Free” – 5mg sodium or less
“Very Low Sodium” – 35mg or less
“Low Sodium” – 140mg or less

“Reduced Sodium”
“Less Sodium”
“Light Sodium”
“Lower Sodium”

“No Salt Added” & “Unsalted” – May still have naturally occurring sodium in the product but generally in a small amount.

Check the label. It still may be too high, depending on the product.
### Sodium Guide

<table>
<thead>
<tr>
<th>Zone</th>
<th>Sodium Content</th>
<th>指导</th>
</tr>
</thead>
<tbody>
<tr>
<td>GREEN ZONE</td>
<td>&lt;5% sodium per serving</td>
<td>Eat these foods throughout your daily diet.</td>
</tr>
<tr>
<td>“All Clear”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>YELLOW ZONE</td>
<td>6-9% sodium per serving</td>
<td>Eat these foods in MODERATION.</td>
</tr>
<tr>
<td>“Slow Down” WARNING</td>
<td></td>
<td></td>
</tr>
<tr>
<td>RED ZONE</td>
<td>&gt;10% sodium per serving</td>
<td>Stop and think about these foods before eating.</td>
</tr>
<tr>
<td>“EMERGENCY”</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

![Apples](image)
## Lower-Sodium Food Choices

<table>
<thead>
<tr>
<th>Food Groups</th>
<th>Food Choices</th>
</tr>
</thead>
</table>
| **Starches** | **Breads:** Rolls, wraps (less than 5% sodium)  
**Cereals:** Shredded wheat, puffed rice or wheat, regular or quick-cook (not instant) oatmeal, farina, cream of wheat, wheatena, cereals with a low percent of sodium  
**Crackers:** Low-sodium, unsalted  
**Rice:** White, brown, wild, basmati (no seasoning packet)  
**Grains:** Plain couscous, quinoa, bulgur (no seasoning packet)  
**Pasta:** Cooked without salting the water |
| **Fruits/vegetables** | **Fruits:** Fresh, canned, jarred and frozen  
**Fruit juices**  
**Vegetables:** Fresh, plain frozen (without sauces/butter/seasonings)  
“No-salt-added” canned vegetables and tomato products  
Low-sodium tomato or low-sodium V8 juices |
| **Milk/Dairy** | **Low-fat milk,** yogurt, sour cream  
**Cheeses:** Swiss, cream, fresh mozzarella, ricotta, low-sodium cottage cheese |
| **Meat/Protein** | **Fresh meats:** Beef, pork, chicken, turkey, veal, lamb (read package to be sure it has not been enhanced)  
**Fish:** Fresh fin fish, scallops, clams, oyster, shrimp  
**Whole eggs,** egg whites, egg beaters  
**Peanut butter,** unsalted nuts and seeds |
| **Desserts** | Ice cream, sherbet, sorbet, popsicles, fudgsicles  
Jell-o, custard  
Sponge cake, pound cake |
| **Condiments** | **Spices:** Any fresh or dried herbs, Mrs. Dash, salt-free McCormick seasoning  
Lemon juice, lime juice  
Regular (not fat-free) mayonnaise, yellow mustard  
**Sauces:** Low-sodium barbeque sauce, Mrs. Dash marinades |
| **Note** | The list of low-sodium foods can go on forever; this list is to give you some ideas. If a food comes in a package, be sure to always look at the label and choose items with a low percentage of sodium (5% or less is ideal). |
Tips for Dining-Out Low Sodium

Want a great tasting meal you can feel good about? “Just ask”!

“Just ask” for:

- Seasonings, rubs or marinades that do not contain salt.
- Baked, broiled or roasted in lemon or wine.
- Dressings, sauces and gravies on the side and use a small amount for flavor.
- Lemon juice or oil and vinegar on salads instead of traditional salad dressings.
- Lean meats cooked without high-sodium ingredients.
- Fresh fruit or salad instead of soup.
- Sherbet or ice cream instead of pastries, pies, pudding, and cake for dessert.

Other tips to follow:

- Carry your own favorite spice or sodium-free spice blend, such as Mrs. Dash.
- Plan ahead and review the menu for the nutrition facts before going out.
- Avoid the bread basket; a roll or slice of bread can add up to 300 mg sodium to the meal.
- Take the salt shaker off the table.
Fluids

Some heart-failure patients may need to limit their fluids. You should discuss this with your provider.

Examples of fluids include:
- soups
- coffee/tea
- milk over cereal
- popsicles

Alcohol and caffeine could potentially make your heart failure worse. They also can affect your medicines and overall heart health. You should discuss this with your heart-failure care provider.
Exercising and Keeping Active

In general, exercising, having sex and driving are OK.

Before you begin any exercise program, please check with your provider first to see what level of activity is right for you. Your provider might recommend a cardiac-rehabilitation program.

Why should I exercise?

• Even small amounts of exercise can improve your heart failure, energy level, weight, blood pressure, blood sugar, stress level, and cholesterol.

• Over time, you should feel stronger – helping you to perform normal daily activities more easily.

• It will make you feel better!

How do I start?

• Choose an activity that you like to do. Start with a few minutes of exercise. You can even start with exercises while lying in bed, then move to a chair, and then move to a standing position.

• Start SLOWLY. Gradually increase the amount of time and the number of days each week that you exercise.

• It is normal to feel tired after exercising, however if you develop any pain, dizziness or extreme shortness of breath, sit down. Call your provider if symptoms are not relieved with rest.
Exercising and Keeping Active

• As a general rule, you should be able to carry on a conversation comfortably while exercising.
• Avoid exercising outside in bad weather or high heat and humidity – choose an indoor activity instead.
• Wait at least an hour after eating.
• Exercising with a friend may be helpful for you to stay motivated.

Warm up, cool down

It’s important to include a couple of minutes of stretching before and after you exercise to avoid muscle cramping/injury and allow your heart rate to slowly increase or decrease.

Tips to Save Your Energy

Some patients find they are easily tired with basic home activities – especially after coming home from the hospital.

• Sit while working whenever possible. Sit while preparing a meal or use a high stool while doing the dishes.
• Minimize the number of trips up and down the stairs during the day.
• Place chairs in several areas around your home to allow rest periods when needed during any activity.
• Allow yourself plenty of time for washing and dressing. Do not rush – you may find you get short of breath.
• Take a bath or shower during the time of day when you feel you have the most energy.
• A shower chair or tub bench and a hand-held showerhead may be helpful instead of standing.

Do NOT use Tobacco

Tobacco products (chew, snuff, cigars, cigarettes, and pipes) are bad for everyone, but especially for those with heart failure.

• All tobacco products tighten arteries and make the heart work harder and can lead to heart attacks.
• Second-hand smoke is just as harmful.

“Just Ask”  Is there help for me to quit smoking?
Start the Conversation

Tell your family about your heart failure

Healthcare begins at birth and lasts a lifetime. And it involves many decisions. Heart failure is a serious condition. For some patients, close monitoring and taking medications at home aren’t enough to keep them feeling well and out of the hospital. Part of living with heart failure is making the decision to do **Advance Care Planning**.

**Advance Care Planning** begins with thinking about what’s important to you

- About your healthcare
- About your life and how you want to live
- About what gives you joy and gives your life meaning

If you aren’t able to make healthcare decisions, who would you want to speak for you so you can live the way you want to live until the very end of your life? It’s part of your quality of life – and the lives of your family members and friends.

You don’t need to talk about it just yet. Just think about it.

- You can start out by writing a letter … to yourself, your family or a friend.
- Having a practice conversation with a friend could help.

**Remember: This is about deciding how YOU want to live the rest of your life.**
It’s not about dying.

You can begin with “What matters to me is
__________________________

For help, go to http://theconversationproject.org.
Start the Conversation

Things to consider:

• Who do you trust to speak for you if you can’t speak for yourself? Have you asked him/her or them?
• What would you want them to say for you? Choosing a “healthcare representative” can help.
  » A healthcare representative is a person you trust to make sure your wishes are carried out if you are unable to speak for yourself.

Some things to keep in mind to plan for the future:

• An Advance Directive (a healthcare representative and/or a Living Will) can help your family and medical team in a medical emergency.
  » They are used only when you can’t speak for yourself.
  » Everyone should have Advance Directives.

If you want to understand more about Advance Care Planning, go to www.prepareforyourcare.org, a website that is simple and easy to use and will help you think about the medical care you might need in the future.

Connecticut has free templates on the internet.

To learn more go to:

“Just ask” your provider:

• If you are having trouble starting this conversation, the palliative team can support you in this process.
What is Palliative Care?

Palliative (pronounced pal-lee-uh-tiv) care is specialized medical care for people with serious illnesses.

It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve the quality of life for both the patient and the family.

Palliative care is provided by a specially trained team of doctors, nurses and other specialists who work together with a patient’s other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

To learn more go to: http://getpalliativecare.org.

Talk with your family and your doctor about your feelings and care wishes.
Testing

In addition to a physical exam, your provider will likely do some additional tests to help figure out how to best treat you. The most common include:

- **Blood tests** – Some medications used to treat heart failure may affect the kidneys, sodium or potassium levels.

- **Electrocardiogram (EKG)** – A picture of the electrical activity of the heart.

- **Echocardiogram (Echo)** – An ultrasound (videos) that show the size, shape and function of the heart and measures the ejection fraction (EF), an estimate of the heart’s pumping strength. A normal EF is 55% or more.

- **Cardiac catheterization (Angiogram)** – A procedure that can look at your blood vessels and measure pressures in your heart and lungs.

Procedures

You may require additional therapies to keep you safe and help you feel better.

- **Biventricular Pacemaker (also called Cardiac Resynchronization Therapy)** – A pacemaker that helps the right and left sides of the heart beat together, which helps the heart pump more effectively.

- **Implantable Cardioverter Defibrillator (ICD)** – A small device that is placed under the skin of your chest that delivers a shock when you are having a life-threatening, abnormal heart rhythm.
Advanced Heart Failure Treatments

For some patients, close monitoring and taking medications at home are not enough to keep them feeling well and out of the hospital.

“Just Ask” if these options are right for you:

• **IV Treatments:** Medicine that goes directly into the vein to take water off your body and help you feel better. It can be given in the hospital, outpatient clinic or at home.

• **Left Ventricular Assist Device (LVAD):** A pump that is placed inside a person’s chest to help a weak heart move blood throughout the body.

• **Heart transplant:** The heart is removed and replaced with a donor heart.
Notes and Questions

Ask a Friend or Family Member to Come to Your Appointments
Notes and Questions