



HEART FAILURE SOCIETY OF AMERICA

Module

4

**SELF-CARE:
Following Your
Treatment Plan
and Dealing with
Your Symptoms**

TAKING CHARGE OF HEART FAILURE

Contents

Important Information	3
Taking Charge of Heart Failure	4
Following Your Treatment Plan	5
Tips for Taking Medication	8
Exercising and Diet	10
Managing Symptoms	13
Weight and Body Swelling	18
Questions and Answers About Self-Care	22
Fatigue	23
Questions to Ask Your Doctor or Nurse	24
Learn More	25
About the HFSA	back cover



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



SELF-CARE

Important Information

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

Health Care Provider Treating Me for Heart Failure:

Name _____

Address _____

City _____ State ____ ZIP _____

Phone _____

Fax _____

E-mail _____

Other Important Phone Numbers:

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

Pharmacy _____

Other health care providers:



TAKING CHARGE OF HEART FAILURE

Introduction

It is possible to lead an active life, even if you have heart failure. Taking control of heart failure is key to your success. You can monitor your heart failure by following the treatment plan prescribed for you. Your care is not just the responsibility of your doctor or nurse. In fact, the success of your treatment plan depends on your active involvement.

This module will help you learn to live successfully with heart failure. It will provide information on:

- Why it is important to follow your treatment plan.
- Tips for following your doctor or nurse's advice.
- Assessing your heart failure symptoms.

It will help you:

- Follow your treatment plan more closely and with less trouble.
- Monitor and attend to your symptoms.

Learn when you should seek immediate help for your symptoms

Taking Charge of Heart Failure

Take charge of heart failure by following your treatment plan. Most heart failure treatment plans include things like consistently taking medicines, changing your diet, weighing yourself every day, and watching for symptoms. Following your treatment plan can make you feel better, prevent your heart failure from getting worse, and help you live longer.

Right now, it may seem hard to follow your treatment plan. Many people feel this way at first. However, taking all of your medicines and making the suggested changes in your life can give you the edge that makes you feel better. Your doctor or nurse can help you overcome barriers that may prevent you from following your treatment plan. That way you can deal with your symptoms before they become a problem, so you can stay out of the hospital.





SELF-CARE

Following Your Treatment Plan

Your doctor or nurse will develop a treatment plan that is right for you. Your plan may include recommendations to:

- Take your medicines exactly as directed.
- Weigh yourself every day to see if you are retaining fluid.
- Follow a low-sodium diet.
- Monitor your symptoms every day.
- Avoid alcohol or drink sparingly (less than 2-3 standard drinks/week).*
- Get vaccinations such as flu shots routinely.
- Control your body weight if you are overweight or have diabetes.
- Get regular physical activity.
- Quit smoking cigarettes and cigars if you smoke.
- Learn when to consult your doctor or nurse.
- Make following your treatment plan a permanent part of your daily life.

*One standard drink is a drink containing 12 grams of alcohol, which usually means 1 can of beer (12 ounces), 1 glass of wine (4 ounces), or 1 shot glass (1.5 ounces) of spirits. One study suggested that this level of alcohol consumption or less was not associated with adverse effects. However, some physicians and nurses believe that these amounts are too much and recommend that patients with heart failure drink no alcohol.



TAKING CHARGE OF HEART FAILURE

Barriers to Following Your Treatment Plan

You may have trouble following your treatment plan because you may:

- Forget to take your medicines.
- Have side effects from your medicines.
- Have trouble going away from home when taking a diuretic (water pill).
- Have trouble paying for your pills.
- Have to get up at night to go to the bathroom.
- Lack time or energy to exercise.
- Be unable to cook.
- Be unable to find the recommended foods or discover they cost too much money.
- Have temptations and cravings that get you off your diet.
- Feel overwhelmed or depressed.





SELF-CARE

Overcoming Barriers to Treatment

Your doctor or nurse can help you overcome the barriers and hurdles you may face in following your treatment plan. For example, they can:

- See if less expensive medicines are available.
- Suggest classes that teach some simple cooking techniques.
- Connect you with other heart failure patients who can teach you ways to better manage your treatment plan to make it work for you.
- Talk with you about your concerns.
- Help you find the best combination of medications with the fewest side effects

Your family and friends can also partner with you. In fact they can be your strongest supporters in helping you overcome barriers to following your program. See *Module 7: Tips for Family and Friends* for specific information on ways they can help you.



TAKING CHARGE OF HEART FAILURE

Tips for Taking All of Your Medicines as Prescribed

- When heart failure patients take their medications, regularly, they feel better and live longer.
- Use a pillbox marked with each day of the week and the times of day you take your medicines. Fill the pillbox at the beginning of each week. Put it in a convenient place. For example, you can place it on the table where you eat or in another spot you go to every day. If you have trouble filling a pillbox, ask a family member to do it for you. Using a pillbox is one of the best ways to remember to take all of your pills every day.
- Put your medicine chart on the back of your medicine cabinet door. That way you can check it easily when you need a reminder.
- Take your medicines at the same time each day. But do not be afraid to change the routine if you have a problem. For example, if you take your diuretic (water pill) in the evening and then find that you have to get up all night to urinate, try taking your water pill earlier in the day.
- If you forget to take a dose of medicine, do not take two doses to make up for the missed one. If another dose is not due for several hours or until the next day, then take the missed dose as soon as you remember. If the next dose is due within a few hours, just skip the missed dose and get back on your regular medicine schedule. *continued*



Module
4

SELF-CARE

Tips for Taking All of Your Medicines as Prescribed (continued)

- If you take medicines that require you to take doses throughout the day, ask your doctor or nurse if you can switch to a similar medicine that you only have to take once or twice a day.
- If you get dizzy after taking your medicines, talk to your doctor or nurse. He or she may need to adjust your medicines, or you may need to space them out during the day.
- If you are having other side effects from a medicine that is bothering you, do not just stop taking the medicine. Talk to your doctor or nurse. He or she can assess your situation and may be able to change your medicine or adjust the dose. Sometimes, the side effects get better over time.
- If you are having trouble paying for your medicines, ask your doctor or nurse about how to get financial help for them. Many drug companies have programs that provide medicines free to low-income patients if a doctor or nurse fills out special forms.
- Another resource patients can use is contacting their pharmacist. Pharmacists can help identify less expensive medications and are more likely to be familiar with the patient's insurance plan(s).

TAKING CHARGE OF HEART FAILURE

Tips for Exercising Regularly

Many people with heart failure are not as physically active as they once were, because they feel too tired or short of breath. Others were never very active in their daily lives. Although physical activity can be hard for people with heart failure, it is very beneficial and worth the effort. You may find the following tips helpful.

First, talk to your doctor or nurse before starting an exercise program. Then:

- Start very slowly and steadily increase your activity level.
- Build a routine for your activity schedule. For example, you may want to walk every evening before dinner.
- Think of your activity or exercise as a special time to do something good for yourself. Schedule it several times a week. Stick to it just as you would an important date.
- Walk, swim, or bicycle with a family member or friend to make it more fun.

See *Module 5: Exercise and Activity* for more tips and information.



SELF-CARE

Tips for Following Your Diet

- If you do not cook, learn one or two simple techniques from a friend or dietitian.
- Do not be afraid to ask a family member or friend to partner with you to help you stay on your diet. In fact this is one of the best ways to stay on your diet and follow other parts of your treatment plan.
- If another member of your family does the cooking, ask him or her to learn how to cook the foods on your diet. Diet changes are easiest when the whole family follows them.

See *Module 2: Following a Low-Sodium Diet* for more tips and information.

TAKING CHARGE OF HEART FAILURE

Other Tips for Following Your Treatment Plan

- Plan ahead. Stick to a routine for your diet, exercise, and taking your medicine. This requires attention to details and active planning. Plan for prescription refills. Allow extra time for food shopping, so that you can read labels. Schedule time for exercise. Planning ahead gives you a little extra room for success when unexpected events happen.
- You may have trouble following your treatment plan during times of travel, increased stress, holidays, or illness. Many people have this problem. If you have a setback or relapse in following your treatment plan, you may feel like you have failed. But your doctor or nurse does not expect you to be perfect. It is never too late to start over and get back on the plan. You will be happy you did.



SELF-CARE

Managing Your Symptoms

It is important to tend to your symptoms as soon as they begin. Like many people, you may fail to notice symptoms in their early stages, or you may shrug them off. But, ignoring symptoms is risky. Symptoms such as trouble breathing, ankle swelling, or weight gain can mean that your heart failure is getting worse. Also, heart failure can get worse “silently.” So if you notice any change in your symptoms (even if the changes are mild) take them seriously. These symptoms can quickly lead to urgent problems requiring a hospital stay.

Monitor your weight and body swelling daily. Keep track of all symptoms. If you do these things, you will be able to notice changes in symptoms early and manage them better. The following sections of this module will help you figure out which symptoms indicate an urgent situation requiring immediate action and which are more common. You will also learn what steps to take for different types of symptoms. As you become more confident in your ability to manage your heart failure symptoms, you may be able to avoid going to the hospital.

TAKING CHARGE OF HEART FAILURE

Symptoms of Heart Failure: When to Call for Help

Heart failure causes many symptoms. Some of them are more serious than others. It is important to recognize when you should call 911 for emergency help and when you should call your doctor or nurse for urgent attention.

The following lists can help you decide what to do if you experience certain symptoms. Detach this chart and keep it in a convenient spot.

Emergency Symptoms of Heart Failure

Call 911 for emergency help if you have:

- Chest discomfort or pain that lasts more than 15 minutes that is not relieved with rest or nitroglycerin.
- Severe, persistent shortness of breath.
- Fainted or passed out.

Urgent Symptoms of Heart Failure

Call your doctor immediately if you have any of the following symptoms:

- Increasing shortness of breath or a new shortness of breath while resting.
- Trouble sleeping due to difficulty breathing. For example, waking up suddenly at night due to difficulty breathing.
- A need to sleep sitting up or on more pillows than usual.
- Fast or irregular heartbeats, palpitations, or a “racing heart” that persists and makes you feel dizzy or lightheaded.

Or if you:

- Cough up frothy or pink sputum.
- Feel like you may pass out.





SELF-CARE

Early Symptoms of Heart Failure

Some symptoms of heart failure are not emergencies, but they can get worse if you do not pay attention to them. Do not ignore early symptoms.

Call your doctor or nurse if you have any of the following symptoms, so they can be treated before they become urgent:

- A weight gain or loss of 2 or more pounds in 1 day, or 4 pounds in 1 week.
- Swelling in the legs, feet, hands, or abdomen.
- A persistent cough or chest congestion.
- Increasing fatigue or a sudden decrease in your ability to do your usual activities.
- A loss of appetite or nausea.
- A feeling of fullness or bloating in your stomach.
- Confusion or restlessness.
- Intermittent or mild shortness of breath.
- Dizziness or lightheadedness.

These common symptoms are early signs that fluid is building up and that your body is producing harmful substances (stress hormones) that worsen heart failure. If you have any of these symptoms, let your doctor or nurse know. They may be able to help decrease or get rid of them. Also let your doctor or nurse know if you think your heart failure medicines are causing you to have new symptoms.

TAKING CHARGE OF HEART FAILURE

Tracking Your Symptoms

It is important to keep track of your heart failure symptoms, so that you can recognize when they are getting worse or whether you are developing new ones.

Use the chart below to list each of your symptoms. Then rate each one on a scale from 1 to 5 based on how you felt last week:

- If a symptom was mild, then rate it as a 1.
- If a symptom was severe, then rate it as a 5.
- If it was somewhere between mild and severe, then give it a 2, 3, or 4 rating.

Using a tracking system like this can help you tell whether your symptoms are getting better or worse, because you will have something concrete to compare them to.

If any of your symptoms are getting worse, contact your doctor or nurse.

Module
4

SELF-CARE

Today's Date:		
Signs and Symptoms I Have Experienced Lately Example: Leg swelling, fatigue, dizziness		Symptom Rating 1=Mild 5=Severe
1		1 2 3 4 5
2		1 2 3 4 5
3		1 2 3 4 5
4		1 2 3 4 5
5		1 2 3 4 5
6		1 2 3 4 5
7		1 2 3 4 5
8		1 2 3 4 5
9		1 2 3 4 5
10		1 2 3 4 5
11		1 2 3 4 5

TAKING CHARGE OF HEART FAILURE

Monitor Your Weight and Body Swelling Daily

Weight gain and/or swelling (also called edema) are signs that fluid is building up in your body. You should take steps to reduce the amount of fluid in your body before it becomes more serious.

Swelling occurs because there is too much sodium (salt) in your body. Extra fluid causes swelling in your ankles and legs. Your shoes may feel tight. You may also notice that your rings feel tight or that you have other swelling in your hands. Some people develop swelling in their abdomen causing clothing to feel tight in the waist.

Checking for weight gain is important. You can gain weight without swelling. The average person can hold about 8 to 15 extra pounds of fluid before developing swelling. That is why one of the best ways to watch for fluid building up is to weigh yourself every day.

The goal is to recognize a change in weight before you develop swelling and other symptoms. That way you can take steps early to remove the extra weight.

Module
4

SELF-CARE

To monitor your weight, you should:

- Write down your weight on the morning of the day after you get home from the hospital. This is probably your dry weight.

Dry weight is your weight without extra body fluid. It is not related to your body size (thin or heavy). Instead, it is related to the amount of fluid retained in your body due to your heart failure.

If you have not been in the hospital recently, ask your doctor or nurse what your dry body weight is.

My dry weight is _____.

- Weigh yourself at the same time, on the same scale, in the same clothes, and in the same way every day. A good way to do this is to get on the scale first thing in the morning after you urinate, but before you eat breakfast and have a bowel movement. If you change the routine for weighing yourself, your weight may change by 2 or more pounds.
- Write your weight down every day. You can use the chart on page 25 to help you chart your weight. To detach the chart, tear along the perforated line.

You can also find the weight chart at: http://abouthf.org/module4/weight_chart.htm. Print the number of copies you need.

Bring your weight chart with you when you visit your doctor.

Compare your weight to your dry weight, not yesterday's weight. Keep your weight as close as possible to your dry weight to decrease the risk of worsening heart failure.

TAKING CHARGE OF HEART FAILURE

Treat Weight Gain and Swelling Right Away

If you gain 2 or more pounds in 1 day, or 4 pounds in 1 week, or if you have more swelling than usual, do the following:

- Cut the sodium (salt) in your diet by 500 mg (about 1/4 teaspoon) each day.
- Decrease the amount of liquid you drink by 1 or 2 cups per day. For example, if you normally drink 5 cups of liquid each day, reduce it to 3 or 4 cups each day for 2 days.

If you do not lose the weight you have gained or decrease your swelling in 1 or 2 days, or if you gain another pound within 2 days, do the following:

- If your doctor has explained how you should adjust your diuretic (water pill) dose in situations like this, follow that advice.
- If your doctor has not explained how to adjust your diuretic, call your doctor or nurse.

Weight Log

Name		Weight Log						
		Sun	Mon	Tues	Wed	Thur	Fri	Sat
Month		Date: Wt:	Date: Wt:	Date: Wt:	Date: Wt:	Date: Wt:	Date: Wt:	Date: Wt:

TAKING CHARGE OF HEART FAILURE

Questions and Answers About Self-Care

Question: Why is it so important to weigh myself every day?

Answer: Sometimes people with heart failure do not understand why their doctor or nurse has asked them to weigh themselves every day. People usually weigh themselves to find out whether they have gained or lost fat. That is not the reason that people with heart failure should weigh themselves every day.

The reason for weighing yourself every day is to find out whether your body is retaining extra fluid. Your weight changes when fluid builds up in your body. The extra fluid makes your heart work harder.

If you detect fluid build-up early (when you have gained just 2 or more pounds) you can treat it at home and decrease the work of your heart. If you detect it later, you are more likely to develop worsening symptoms and may have to go to the hospital for treatment.

That is why it is important to get into the habit of weighing yourself every day.



SELF-CARE

Prevent Fatigue from Interfering with Your Life

Fatigue is a common problem for patients with heart failure. You may be surprised to learn that the best treatment for fatigue is physical activity. Refer to the tips for exercising regularly earlier in this module or see *Module 5: Exercise and Activity* for more detail.

Sometimes fatigue is an early symptom of worsening heart failure. Call your doctor or nurse for overwhelming and increasing fatigue.

If fatigue continues, try these tips:

- Plan for adequate sleep and rest periods.
- Group similar activities such as carrying items up stairs.
- Use energy saving ways of doing your usual activities:
 - Do not try to do too much at one time. Schedule things at varying times throughout the day, so you can alternate periods of activity and rest.
 - Ask your family and friends for help.
 - Sit while you are taking a shower or doing other grooming activities.
 - Wear clothes with zippers and front openings to decrease the effort of dressing.

TAKING CHARGE OF HEART FAILURE

Other Questions to Ask Your Doctor or Nurse

Am I a candidate for a flexible diuretic (water pill) regimen?

(A flexible diuretic regimen is one in which you adjust your water pill dose up or down as needed based on your weight.)

Reason for asking this question:

Some patients can monitor their heart failure symptoms well and can tell when they need a little higher dose of their water pill. They are in tune with their bodies, weigh themselves routinely, and pay close attention to changes in their symptoms.

If you also do these things, your doctor may direct you to take an extra diuretic (water pill) when you gain a specified amount of weight.

Do not do this on your own, because the regimen varies for every person. But, if you believe that you are a candidate for a flexible diuretic (water pill) regimen, ask your doctor.

Should I have a flu shot this year? What about the pneumonia vaccine?

Reason for asking this question:

Caring for yourself is all about balance. The goal is to stay well rather than to treat problems. One way to stay well is to avoid getting the flu or pneumonia. Safe vaccines (shots) that can keep you from getting sick are available.

Get a flu shot every year. Ask your doctor or nurse if you should get the pneumonia vaccine too.

How much alcohol can I drink?

Reason for asking this question:

Alcohol can damage the cells of the heart and make it harder for your heart to pump blood. If you have heart failure, your heart is already pumping less effectively. So it makes sense not to drink alcohol at all or to drink sparingly.

To drink sparingly means to drink less than 2-3 standard drinks/week. One standard drink is a drink containing 12 grams of alcohol, which usually means 1 can of beer (12 ounces), 1 glass of wine (4 ounces), or 1 shot glass (1.5 ounces) of spirits.

Talk to your doctor or nurse if you have questions about alcohol consumption.



SELF-CARE

Learn More

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

The topics covered in the other modules include:

- *Introduction: Taking Control of Heart Failure*
- *How to Follow a Low-Sodium Diet*
- *Heart Failure Medicines*
- *Exercise and Activity*
- *Managing Feelings About Heart Failure*
- *Tips for Family and Friends*
- *Lifestyle Changes: Managing Other Chronic Conditions*
- *Advance Care Planning*
- *Heart Rhythm Problems*
- *How to Evaluate Claims of New Heart Failure Treatments and Cures*

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



About the Heart Failure Society of America, Inc.

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

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