

Tips for Family and Friends

The Heart Failure Society of America (HFSA) is a non-profit organization of health care professionals and researchers who are dedicated to enhancing quality and duration of life for patients with heart failure and preventing the condition in those at risk. These educational modules have been developed to help patients, their families, and individuals at risk for heart failure understand and cope with the disease. For more information about the Society please visit our web site www.hfsa.org.



www.hfsa.org

Heart Failure Society
of America

Contact Information

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

Doctor Treating Me for Heart Failure:

Name:

Address:

City:

State:

Zip:

Phone number:

Fax:

E-mail:

Other Important Phone Numbers:

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

Pharmacy:

Other doctors or nurses:

Introduction

Most people do not live in isolation and are strongly affected by the people around them. Therefore, family members and friends can play an important role in supporting a person with heart failure and helping him or her live as well as possible with the disease. This module is for family and friends of patients with advanced/severe heart failure, that is, patients who require help with day-to-day activities.

Many patients with heart failure continue to lead normal active lives and will not become sicker or disabled. See Module 4 on Self Care for information for patients diagnosed with heart failure who continue to enjoy a normal active lifestyle.

In general, you can best provide support by learning about heart failure and the patient's treatment plan. Family and friends can be particularly effective in watching for changes in symptoms and in helping a person with heart failure stay on a low-sodium diet and increase his or her physical activity. But because each person is an individual and has differing goals, needs, and abilities, communication about how you can best provide support is important.

Introduction (*cont.*)



This module will focus on specific things that family members and friends can do to help a person with heart failure. It may be helpful to have the other modules in this series nearby for reference as you read this module.

This module will provide information on how family and friends can help a person with advanced/severe heart failure:

- Recognize changes in symptoms.
- Follow a low-sodium diet.
- Become more active.
- Remain independent but safe.

It will help family and friends learn:

- Why support is a vital part of a heart failure treatment plan.
- How to increase the overall level of support the person with heart failure receives.
- How to promote good self-care behaviors.



Helping with Symptom Monitoring

It is important to monitor symptoms to determine if they are getting worse. Noticing changes in symptoms early and taking the appropriate steps to manage them can prevent urgent problems that might require a hospital stay. Sometimes it is hard for people with heart failure to recognize changes in symptoms. So family and friends can help by monitoring symptoms along with the patient.

Family and friends can help a person with heart failure monitor symptoms by:

- Telling the patient about any changes in his or her symptoms or condition that you notice, even if they are small.

For example, if you notice increased shortness of breath, mental confusion, or ankle and leg swelling, tell the patient and contact his or her doctor or nurse.

- Helping the patient weigh him or herself every day and keep a record of weight. Changes in a heart failure patient's daily weight can provide important information about whether the patient is retaining extra fluid that can be harmful.

For example, if the patient's weight increases by four (4) pounds over the course of a week, he or she may be retaining too much fluid. You or the patient should call the doctor, so the fluid retention can be treated early before it gets worse.

- Observing the number of pillows the patient uses to keep from being short of breath during the night.

If the person with heart failure needs more pillows, it is important to inform the patient's doctor or nurse.

- Helping the patient with heart failure problem-solve if he or she develops symptoms of an upper respiratory tract infection or the flu.

If a person with heart failure develops the flu or an upper respiratory tract infection occurs, it may be difficult to tell if the heart failure is getting worse or if the symptoms are solely due to the infection or virus. In general, an appointment to see the doctor or nurse is probably in order.

Decongestants should be taken with caution. Before taking an over-the-counter decongestant for flu or an upper respiratory tract infection, check with your doctor or nurse.

For relief of pain, aches and fever, it is preferable to take acetaminophen and avoid non-steroidal anti-inflammatory medicines, sometimes called NSAIDs (aspirin, ibuprofen and others).

Refer to Module 4: Self-Care: Following Your Treatment Plan and Dealing with Your Symptoms for more detailed information on monitoring and managing symptoms of heart failure.

Helping with Diet Recommendations

Food preparation and eating are social activities that often involve family and friends. So it is helpful for all members of the household to understand the diet recommendations for the patient with heart failure, even if you are not the one who prepares food. Diet changes are easier when the whole family follows them.

Because people with heart failure should eat a low-sodium diet, it is especially important to understand this diet and how to follow it.

Family and friends can help a person with heart failure follow a low-sodium diet by:

- Finding out the amount of sodium allowed in their diet.
- Talking about food likes and dislikes, and concerns about following a low-sodium diet.
- Involving the patient with heart failure in meal planning and adapting meals to low-sodium versions.
- Learning how to read labels, so you can calculate the sodium content when buying food or preparing meals.
- Learning ways of preparing food that require less sodium.
- Looking for low-sodium recipes.
- Preparing some low-sodium foods and snacks, when planning parties, family events, or holiday gatherings.

- Preparing extra servings of low-sodium foods that can be refrigerated or frozen, so the patient with heart failure can eat a healthy meal at a later time without cooking.
- Paying particular attention to food selection when eating at a place outside of the normal environment. Remember that approximately 70 percent of the sodium we eat each day is “hidden” in food that might not taste salty.

Be aware that most foods sold at concession stands are high in sodium. Bring healthy snacks to places such as movie theaters or sporting events where high-sodium foods are usually eaten. Or, eat a healthy meal at home or at a restaurant before going to the event.

When choosing restaurants, avoid places that serve only fried or pre-prepared foods. Most fast-food restaurants fall in this category as well as some family or bistro type restaurants. Because these restaurants typically do not cook the meals from scratch themselves, it is difficult for these establishments to decrease the sodium level in the foods served.

Make it a point to inform the waiter that the food should not be prepared with salt or monosodium glutamate (MSG).

Refer to Module 2: How to Follow a Low-Sodium Diet for additional details on how to follow a low-sodium diet and why a low-sodium diet is an essential part of a treatment plan for a person with heart failure.

Helping with Activity and Exercise

Keeping active can help a person with heart failure feel better, decrease symptoms, and improve heart function. But remaining active may be very difficult.

Family and friends can help a person with heart failure become more active and enjoy it more by:

- Encouraging the person with heart failure to be as active as possible.
- Taking walks and participating in activities. Exercise and activity are always more fun when they feel like a social event.

Refer to Module 5: Exercise and Activity for specific information on starting and maintaining an activity program.



Other Ways to Help with the Treatment Plan

Taking all medicines as directed and checking for weight gain are important parts of a heart failure treatment plan.

Family and friends can help with these tasks by:

- Filling a pillbox for the patient with the medicines that he or she is to take each day of the week.
- Helping the person with heart failure weigh him or herself each day and tracking the results on a weight chart.

Teaching Good Self-Care Behaviors

Research shows that when individuals have confidence in their ability to do something, they are more likely to follow through, even under stressful conditions. Family members and friends can teach positive behaviors and encourage the person with heart failure in their efforts to manage self-care. Examples include helping the patient learn to read food labels to pick out low-sodium foods, the importance of taking medicines as prescribed by the doctor, and helping the patient recognize early symptoms of worsening heart failure.

Refer to Module 4: Self-Care: Following Your Treatment Plan and Dealing with Your Symptoms for additional information about the importance of self-care.

Helping with Daily Activities

Some people with heart failure are motivated to practice self-care without much support. Others enjoy or need the help and support of family and friends to manage daily activities. Honest communication about goals, needs, and desires is important. The patient's doctor or nurse can also assist in making connections with people and groups who are available to help. Do not hesitate to use them to provide a link to others.

You can help a person with heart failure remain independent but safe by discussing topics such as driving and living arrangements and providing assistance as necessary.

Driving

There are no set rules for heart failure and driving a car. Factors to consider are whether the person with heart failure has physical or mental changes that impair his or her ability to drive. Such changes include excessive fatigue, decreased alertness, confusion, memory lapses, or other signs of slowed mental processes. If you are concerned, discuss it with the patient's doctor or nurse.

Living Arrangements

There are no set rules on the best living arrangements for a person with heart failure. Each situation is different. A person with heart failure may want to stay in a house or neighborhood that is familiar, even though it may not be as practical as another type of living arrangement.

It is important to discuss the pluses and minuses of moving. Writing down the advantages and disadvantages of the patient moving or staying in his or her current residence can help with the decision-making process.

Support from family or friends can play a role in deciding where the patient should live. For example, family and friends can help with heavy chores such as taking out the garbage, mowing the lawn, grocery shopping, doing the laundry, heavy cleaning, and lifting.

Remember, even if family and friends think they have an ideal solution such as having the person with heart failure move in with them, the change may mean a loss of independence. The move may be easier if the patient recognizes the need for help and support.

Emotional and Social Support



People with heart failure who have emotional support from family and friends often feel better and have a more positive outlook on life. Many people with heart failure also find that getting involved socially helps them keep their mind off their symptoms and improves their quality of life.

Family and friends can offer emotional support to a person with heart failure by:

- Discussing their heart failure treatment plan.

Let the patient know when he or she is doing a good job of following the prescribed self-care plan and making lifestyle changes such as following a low-sodium diet and increasing their activity level. This encourages the patient to continue and lets the patient know that you have noticed his or her actions.

Also, try to avoid critical comments when the patient's self-care behaviors are not as good as they could be. Instead, discuss ways that you might help the patient manage self-care better.

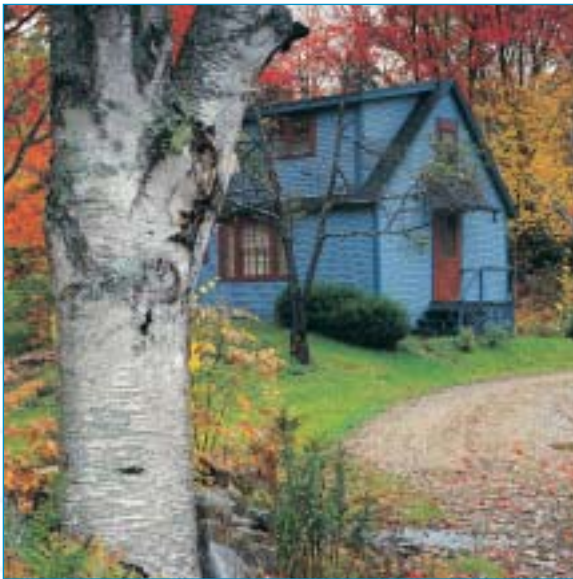
- Allowing the person with heart failure to make decisions about health care and lifestyle behaviors.

If you want to help with decision-making, offer choices, but limit the number of choices so as not to confuse the patient. For example, when discussing what to have for dinner, offer two low-sodium choices, and let the person decide which one he or she would prefer.

- Providing positive reinforcement when you see improvements in the person's condition, symptoms, or ability to do activities.



Emotional and Social Support (*cont.*)



- Discussing feelings and fears about heart failure.

If you think the patient is depressed or anxious, discuss it with them. There are many things that can be done to manage these feelings, but the first step is recognizing them.

- Asking the patient if he or she would like to visit with someone from a pastoral care service. Affirm choices regarding faith based or other type of spiritual support.

Refer to Module 6: Managing Feelings About Heart Failure for more information on recognizing and managing feelings of depression and anxiety.

You can offer social support by:

- Visiting, calling, sending e-mail, or communicating through other means on a regular basis.
- Inviting the patient to a planned event such as a baseball game, family birthday or anniversary celebration, movie, play, or concert.
- Helping the person with heart failure meet his or her work goals if the person is returning to work.
- Encouraging the person with heart failure to establish social networks by getting involved in group activities such as heart failure support groups, cardiac rehabilitation programs, church groups, senior programs, and other social groups.

Other Ways to Provide Support

Financial Matters

Sometimes a person with heart failure may have trouble following his or her treatment plan because of financial barriers. If this is the case, friends and family can help by asking health care providers about financial assistance programs for:

- Hospital and outpatient clinic fees. The hospital social worker is a good source of information on state and federal programs.
- Medicines. Many drug companies have programs that provide medicines at reduced cost or free to low-income patients. But the application process can seem difficult to someone who is ill. Ask the patient's doctor or nurse about the programs, and help the patient fill out the forms.
- Durable medical equipment such as oxygen. Insurance may cover some of the cost. Ask the doctor or nurse for information.

Talking with the Doctor or Nurse

Talking with the doctor or nurse will help insure that the patient gets the best possible care. If the person with heart failure is not comfortable asking questions, family and friends can help.

But it is always a good idea to ask the questions in front of the patient. That way everyone hears the same information, and there will be less chance for misunderstanding. It also helps maintain the patient's trust in the health care team.

Discussing Advance Care Planning

While it may be difficult to discuss death and dying, everyone benefits by knowing the wishes of the patient. Patients and families should discuss among themselves what to do in the event of an emergency, especially one involving a heart attack. In addition, it is important to discuss topics associated with advance care planning such as a living will.

Sometimes family members and friends may think it is better to remain quiet about advance care planning, because they do not want to rock the boat, or because they feel the patient has been through enough already. But in fact, many patients are relieved that someone is willing to talk to them about their desires related to death and dying. Knowing that everyone involved in making advance care planning decisions understands the patient's preferences can lessen the burden when decisions have to be made.

Communicating about advance care planning in a loving and caring way can help make these discussions easier. One way to begin talking about the topic is to tell the patient what you see or feel. For example, you can start by saying:

- "It seems like you are more tired than you were in the past. What can we do to make you feel better?"
- "What can we do to make your life easier?"
- "We want to make you as comfortable as possible, but we don't know what you want most. What should I / we focus on?"

Refer to Module 8: Advance Directives for more information on end-of-life care.

Care for the Caretakers

Family and friends who assume responsibility for caring for someone with advanced heart failure can run the risk of feeling overly burdened by the demands of such care. Your own quality of life or health can suffer as a result. For this reason, it is important for you to take care of yourself too. You can do so by:

- Taking advantage of resources offering social and emotional support for family members and friends, so you have an opportunity to speak freely about your feelings, concerns, and frustrations.
- Arranging for assistance with your care-giving duties. Some hospitals or organizations can provide "respite care" service, so that someone can provide expert care for several hours a day on a routine basis to give the usual caregiver a rest.
- Getting enough sleep, exercising regularly, and eating well-balanced meals.



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, as they become available. Or you can check the Heart Failure Society of America web site 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
- Self-Care: Following Your Treatment Plan and Dealing with Your Symptoms
- Exercise and Activity
- Managing Feelings About Heart Failure
- Lifestyle Changes
- Advance Directives
- 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.

