HFSA
HEART FAILURE SOCIETY OF AMERICA

MODULE
7

Tips for
Family and Friends

Contents

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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. HFSA developed these modules to help patients, their families, and individuals at risk for heart failure understand and cope with the disease. For more information about the HFSA, please visit our website www.hfsa.org.

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.

Know Who to Contact

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

Healthcare 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 healthcare providers:

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Introduction

Normally, people do not live in isolation, and, therefore, they are strongly influenced by the people around them. When a disease affects a given person, those with close relationships to that person will also be affected in some way, either directly or indirectly. For persons suffering from heart failure, family members and friends can play an important role in lending support and helping that person cope with their disease. Friends and family can help their loved one live as well as possible with their disease. This module is for family and friends of people with advanced or severe heart failure—people who require help with day-to-day activities.

Many people 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 people 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 person's treatment plan. Family and friends can be particularly effective in watching for changes in symptoms; helping a person with heart failure stay on the proper diet that is low in sodium; and encouraging an increase in 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. 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

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Helping with Symptom Monitoring

For people suffering with heart failure, it is important to monitor symptoms and to be mindful if they are getting worse. Noticing changes in symptoms early and taking the appropriate steps to manage them may prevent more urgent problems that might require a hospital stay. Sometimes it is hard for people with heart failure to recognize changes in symptoms. At times, a friend or family member may recognize worsening symptoms of which the person with heart failure may not necessarily be aware. In this way, family and friends can be very helpful in monitoring symptoms that might indicate a change in someone's condition.

As a family member or a friend of a person with heart failure, you can help him or her monitor symptoms by:

- Telling the person with heart failure about any changes in his or her condition that you notice, even if the changes are small.

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

- Helping the person weigh him or herself every day and keeping a record of weight. In a person with heart failure, changes in daily weight can provide important information about whether the person is retaining extra fluid. Extra fluid in the body can be harmful.

For example, if the person'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 person should call the doctor or the nurse, so the fluid retention can be treated early before it gets worse.

- Observing the number of pillows the person 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 person's doctor or nurse.
- Helping the person 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, it may be difficult to tell if their heart failure symptoms are getting worse or if the symptoms are solely due to the infection. In general, an appointment to see the doctor or nurse is probably in order.

In the case of someone with heart failure getting a cold or flu, decongestants should be taken with caution. Before taking an over-the-counter decongestant for flu or an upper respiratory tract infection, check with the doctor or the nurse of the person with heart failure.

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

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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. It is helpful for all members of the household to understand common diet recommendations for the person with heart failure, even if you are not the one who prepares food for that person. Diet changes are easier when the whole family follows them.

In those with heart failure, eating a lot of sodium will usually lead to fluid retention and worsening symptoms. People with heart failure should therefore eat a low-sodium diet; it is important to understand this diet and how to follow it.

You can help a person with heart failure follow a low-sodium diet by:

- Finding out the amount of sodium allowed in his or her diet.
- Talking about food likes and dislikes and concerns about following a low-sodium diet. Involving the person 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. This will help the person with heart failure eat a healthy meal without cooking at a later time.
- 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. You can also choose to eat a healthy meal at home or at a restaurant before going to an event.

When choosing restaurants, avoid places that serve only fried or pre-prepared foods. Most fast-food restaurants fall into this category as well as some family or bistro type restaurants. These restaurants typically do not cook the meals from scratch. Thus, it is difficult for these establishments to control the amount of sodium 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).

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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 while also decreasing their symptoms to some degree. Remaining active, however, can also be very difficult because this may bring on unpleasant or unwanted symptoms such as excess fatigue or shortness of breath. Choosing the right level of activity can therefore pose a challenge, trying to balance symptoms of heart failure with the need to achieve some activity every day.

You 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.
- Realizing that it is important not to place excess pressure on people with heart failure to be more active. If their ability to be active is extremely limited, this may lead to resentment and conflict.

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.

You can help with these tasks by:

- Filling a pillbox for the person 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. You can teach positive behaviors and encourage the person with heart failure in their efforts to manage themselves better.

Examples include helping the person learn to read food labels to pick out low-sodium foods, stressing the importance of taking medicines as prescribed by the doctor or the nurse, and helping the person 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 needs. Honest communication about goals, needs, and desires is important. The person's doctor or nurse can also assist in making connections with people or groups who are available to help. Do not hesitate to use them to provide more information.

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 may 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 person'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. Sometimes this may not be as practical, and another type of living arrangement may be more appropriate or safe. In this instance, it is important to discuss the pluses and minuses of moving. Writing down the advantages and disadvantages of the person with heart failure moving or staying in his or her current residence can help with the decision-making process.

Support from family or friends can play a critical role in deciding where the person suffering from heart failure might live. For example, if you or others can offer help with chores such as taking out the garbage, mowing the lawn, grocery shopping, doing the laundry, and cleaning, that person just might be able to remain in their home for the time being.

Remember, even if you think you have an ideal solution such as having the person with heart failure move in with you or other people, the change may mean a loss of independence. The move may be easier if the person with heart failure 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 find that getting involved socially helps them keep their mind off their symptoms and improves their quality of life. You can offer emotional support to a person with heart failure by:

- Discussing their heart failure treatment plan. Let the person with heart failure 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 person to continue and lets the person know that you have noticed his or her actions. Also, try to avoid critical comments when the person's behaviors are not as good as they could be. Instead, discuss ways that you might help the person manage their own 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 person. 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.

Discussing Feelings and Fears

If you think the person with heart failure is depressed or anxious, discuss it with him or her. There is much that can be done to manage that type of feeling, but the first step is recognizing it. In this circumstance, you could help by considering the following:

- Ask the person 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 also offer emotional support by:

- Visiting, calling, sending e-mail, or communicating through other means on a regular basis.
- Inviting the person with heart failure to a planned event such as a baseball game, family birthday or anniversary celebration, movie, play, or concert.
- Helping the person meet his or her work goals if the person is returning to work.

- Encouraging the person 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.

Financial Matters

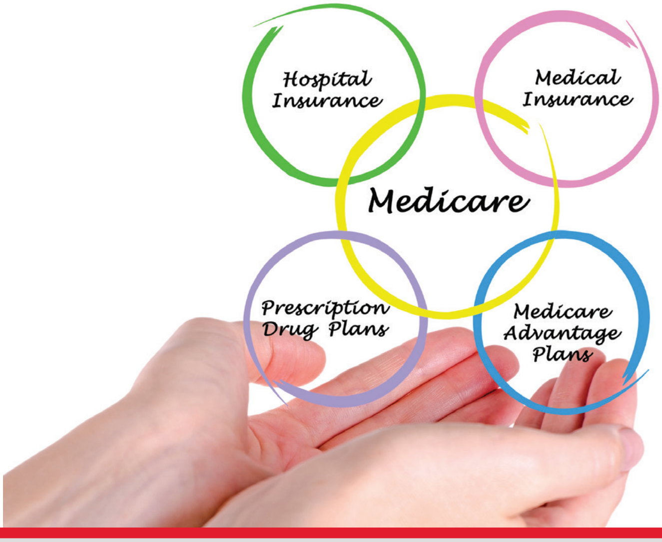
Sometimes a person with heart failure may have trouble following his or her treatment plan because of financial barriers. If this is the case, you can help by asking healthcare providers about financial assistance programs for:

- 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 people with heart failure. The application process can seem difficult to someone who is ill. Ask the person's doctor or nurse about the programs, and help the person 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 ensure that the person with heart failure gets the best possible care. If the person with heart failure is not comfortable asking questions, you can help.

It is always a good idea to ask the questions in the presence of the person with heart failure. That way, everyone hears the same information, and there will be less chance for misunderstanding. It also helps maintain the person's trust in the healthcare team.



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Discussing Advance Care Planning

Advanced care planning refers to a given person outlining his or her wishes for medical treatments in the event of a severe or catastrophic illness before it happens. For people with chronic heart failure it is important to discuss topics associated with advance care planning such as a living will. A living will is a legal document that outlines a person's specific wishes in the case where they become mentally impaired or unable to voice their wishes in the event of a severe illness. While it is difficult to discuss death and dying, everyone benefits by knowing the wishes of a person to whom they are close. People with heart failure and their families should discuss among themselves what to do in the event of an emergency, especially one involving a heart attack that may cause death. Knowing a person's wishes up front can be helpful with decision-making on the part of that person's family if something like this should ever occur.

Sometimes family members and friends may think it is better to remain quiet about advance care planning. This is because they do not want to make the person with heart failure upset, or because they feel the person has been through enough already. In fact, many people with heart failure are relieved that someone is willing to talk to them about their wishes related to death and dying. Knowing that everyone involved in making advance care planning decisions understands the person'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 person what you see or feel. For example, you can start by asking:

- "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 we focus on?"

Refer to Module 9: Advance Care Planning for more information on end-of-life care.

Care for 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. This is also known as "burn out." 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. 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 about Heart Failure, Treatment, and Self-Management

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 Medications
- Self-Care: Following your Treatment Plan and Dealing with your Symptoms
- Exercise and Activity
- Managing Feelings about Heart Failure
- Tips for Family and Friends
- Lifestyle Changes: Managing other Chronic Conditions
- Advance Care Planning
- How to Evaluate Claims of New Heart Failure Treatments and Cures
- Heart Rhythm Problems
- Clinical Trials

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 healthcare provider.

Notes

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.

Complimentary HFSA Patient Resource Available!

Heart Failure Storylines mobile app allows patients and caregivers to track appointments, mood, symptoms, and more on the same timeline as their treatment. It gives an accurate, shareable record of patient experiences between physician visits and helps care teams collaborate on treatment strategies. The app is useful for someone living with Heart Failure as well as a caregiver. Learn more today visit www.hfsa.org.

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