



Physicians

HEART & LUNG
CENTER

Caring for a Person with Heart Failure

Caring for someone with heart problems can be a challenge. There may be a lot of medical information to understand, and you may not know exactly where to start. Here are some simple things that you can do to help improve the health of the person under your care. This is not a complete guide to all issues you will face, so remember to discuss any questions you have with the person's doctor or nurse, and to use the additional resources listed at the end of this document.

Understanding the Patient's Medical Condition

It can be difficult to have a clear understanding of all the heart-related issues the patient faces. Make sure that you ask the doctor or nurse for any educational materials or resources that they find useful; and don't be afraid to ask questions. It is often useful to bring a written list of questions with you to office visits.

Observing Symptoms

It is important to watch for changes in symptoms. A change may mean that the same symptoms are getting worse or that new symptoms have appeared that you haven't seen before. Any change in symptoms can be a sign that more urgent care is needed. A person with heart problems may have trouble noticing these changes, so a caregiver can be very helpful in pointing them out. Talk with the patient if you notice changes in his or her symptoms. Encourage the patient to get on the scale and measure weight daily. Changes in weight can be a sign of changes in health.

Below is a table of signs and symptoms seen in those with heart failure:

Common Symptoms	Less Common but Important Symptoms
<ul style="list-style-type: none">• Shortness of breath when active• Trouble breathing when sleeping• Weight gain of more than 3 pounds overnight or 5 pounds in 1 week• Swollen legs and/or ankles• Decreased appetite• Having to urinate during the night• Feeling tired	<ul style="list-style-type: none">• Shortness of breath when at rest• Dizziness, lightheadedness, and/or passing out• Irregular heartbeat• Nausea and/or abdominal bleeding• Chest pain• Poor memory

Responding to Symptom Changes

If you observe symptom changes, immediately contact the doctor or nurse who is treating the patient's heart problems. Often they have given you detailed instructions on when to call for a change in symptoms. If you are ever in doubt, call and ask for advice.

Dealing with Other Illnesses

If you have questions or concerns about the patient's health with regard to conditions that are *not* related to the heart, you should contact the doctor currently treating those conditions or the patient's primary care doctor.

Helping with Medicine and Treatment Orders

Follow doctor's orders carefully to gain the most benefit from medical treatment. As a caregiver, you can help by setting a healthcare routine. Make sure that the right medications are always available and that pills are taken exactly as the doctor ordered. By filling up weekly pillboxes, you can help the patient follow his or her medications properly.

Understanding Implantable Devices

Some patients may have an implantable device, such as an implantable cardioverter defibrillator (ICD), placed in his or her heart to correct an abnormal, fast heart rhythm if it occurs. These devices vary in size and work by monitoring the heart's activity. If the device detects a problem in the heart rhythm, it releases a small amount of electricity – a shock – to the heart in order to reset the rhythm to a normal one. Most patients are aware of a shock when it occurs. It is important to make a plan with the patient and the doctor or nurse so that you know what to do if a shock occurs. Having an action plan will reduce confusion and anxiety for the patient and for you. There is certain information that you should have available at all times: (1) the ICD identification card; (2) a list of medications; and (3) the doctor's name and phone number.

A sample device action plan is shown below. You should discuss the specific action plan that is best for the patient with their doctor or nurse:

Event	Symptoms	Action
Received ICD shock	Feeling fine	Call heart doctor to discuss the event and arrange appropriate follow-up
Received ICD shock	Experiencing chest pain or pressure, shortness of breath, rapid heart action; feel dizzy, confused, or not well	Seek medical attention immediately
Received two or more ICD shocks within 24 hours	Feeling fine or ill	Seek medical attention immediately

Source: Sears SF Jr, Shea JB, Conti JB. *Circulation*. 2005;111(23):e380-e382.

If the patient receives a shock, comfort them as best you can and stay with them. Help them remain calm and not move around until the shock experience is over. You will **not** be harmed by the shock if you touch the patient. If the patient passes out, call an ambulance immediately. Even if the patient feels fine after a shock, it is important to call the doctor for further instructions.

Helping with Diet and Exercise/Physical Activity

A proper diet and regular exercise can help someone with heart failure feel better and stay out of the hospital. As a caregiver, you can first help by offering positive encouragement. You can also prepare meals that are low in sodium (salt) and fat, as directed by the doctor or nurse. Read food labels carefully and note the serving size and the amount of sodium, fat, and cholesterol in each serving. An example of a food label is shown here:

The image shows a food label for Nonfat Milk. Two arrows point to specific parts of the label: one points to the 'Serving Size 8 fl oz (240mL)' and the other points to the 'Sodium 130mg' entry.

Nonfat Milk	
Serving Size 8 fl oz (240mL)	
Servings Per Container 2	
Amount Per Serving	
Calories 80	Calories from Fat 0
% Daily Value*	
Total Fat 0g	0%
Saturated Fat 0g	0%
Cholesterol less than 5mg	1%
Sodium 130mg	5%
Total Carbohydrate 12g	4%
Dietary Fiber 0g	0%
Sugars 11g	
Protein 8g	
Vitamin A 8% • Vitamin C 4%	
Calcium 30% • Iron 0% • Vitamin D 25%	
* Percent Daily Values are based on a 2,000 calorie diet. Your daily values may be higher or lower depending on your calorie needs.	
	Calories: 2,000 2,500
Total Fat	Less than 85g 80g
Sat Fat	Less than 20g 25g
Cholesterol	Less than 300mg 300mg
Sodium	Less than 2,400mg 2,400mg
Total Carbohydrate	300g 375g
Dietary Fiber	25g 30g

Source: National Heart, Lung, and Blood Institute Therapeutic Lifestyle Diet.

Food labels often contain goals of 2,400 grams of sodium per day, but for patients with heart failure this is too high. A low-sodium diet has less than 2,000 mg of sodium (salt) per day and can help prevent or reduce shortness of breath and swelling in the feet and ankles. Since most sodium (salt) is in non-fresh foods, it helps to stay away from foods that are canned, frozen, boxed, or packaged in a bag. Also, do not add salt during cooking, food preparation, or at the table. High levels of sodium are found in salad dressings, cheese, lunchmeats, and other commonly consumed “processed” foods, even when they do not taste salty. That is why it is important to read food labels for sodium content. Be careful when eating at restaurants. Many restaurants will provide you with nutritional information if you ask for it. If you tell them not to add salt when cooking or to give you your salad dressing or sauce on the side, they will do this. Also pay attention to foods that contain a large amount of water, such as head lettuce or watermelon.

Patients with heart failure should remain as physically active as possible, and you can help the patient with whatever activities the doctor or nurse recommends. A healthy way to incorporate exercise into your own routine is to join them in their exercise activities. Participating with them will help to keep both of you motivated to stay active. Walking is the best exercise for patients with heart failure. They should start with 5 minutes of continuous walking and gradually increase to a goal of 45 minutes per day. Remember to warm up and cool down properly by stretching slowly and walking at a slow to moderate pace for about 5 minutes both before and after completing an exercise session.

Driving a Car

Follow the doctor or nurse's instructions about whether or not the patient is able to drive. Rules vary from state to state for persons with an ICD.

Living Arrangements

Talk to the patient and the doctor about the living arrangement that would be best. While some patients with heart-related health issues live and work independently without assistance, some need daily nursing care at home and others need to live in an environment where care is available all day long. There are a lot of issues to take into account when making this decision. Take your time and talk about what would be practical and best for the patient's health.

Emotional and Social Support

It is important to discuss the patient's health in an open and honest way that allows emotions to be expressed. Health issues may cause frustration for the patient, but talking about how they are feeling may help relieve stress. Having the support of family and friends can also make a patient feel better and more positive. You can help the patient socialize with the people they care about, even if illness may make this difficult. Having an active social life can help get a patient's mind off of health concerns and focus on something more enjoyable.

Communicating with Doctors and Nurses

Good communication between the patient and their doctor or other health professionals can help them get the best care possible. Write down questions before the next doctor visit. This will help the patient remember to ask about their concerns and get their questions answered. Taking notes about the answers is helpful too. Get in the habit of bringing **all** medications, both prescribed and over-the-counter substances such as vitamins, herbs, or supplements, to every office visit. Make sure to keep an up-to-date list of all medications, and to keep them refilled. At the office visit, you can also help by listening carefully with the patient to what the doctor says and taking notes.

Advance Directives

It is difficult to talk about death and dying with someone close to you, but it is something you may need to do. You can help the patient make plans about where to go and whom to call in an emergency. They may also want to talk about legal issues like making a living will or a healthcare durable power of attorney. Many patients will be relieved that someone close to them is willing to talk honestly about death.

Financial Concerns

Good healthcare can be expensive, but there are ways to make this burden easier. Talk to a social worker at the hospital about government assistance programs. Also, some drug companies offer medicine at a lower cost for those who qualify based on income. Talk to your doctor, nurse, or social worker about these programs.

Taking Care of Yourself

As the caregiver, you must look out for your own health as well. Take advantage of any help offered by friends and family. It is not unusual to feel overwhelmed, anxious, or depressed when taking on responsibilities for another person. Make sure you have someone that you can talk to, obtain regular physical activity, eat a balanced diet, and get adequate rest. Your health is important too. If you have any questions or concerns, you should ask for help from people around you, including the healthcare professionals in your area. Taking care of someone can be very difficult, but with resources and support from your community, you can still have a healthy and happy life.

Additional Resources

There are several resources available to help you in your role as a caregiver. These organizations have more information about heart problems:

- American Association of Heart Failure Nurses (www.aahfn.org)
- American Heart Association (www.americanheart.org; 1(800) 242-8721)
- Heart Failure Society of America (www.hfsa.org; 1 (651) 642-1633)
- Heart Rhythm Society (www.hrsonline.org; 1 (202) 464-3400)

Developed by the SCA Prevention Medical Advisory Team.

This material is intended to be educational. It is not intended to replace the information provided to you by your healthcare providers and may not be directly applicable for your individual clinical circumstance.

Please refer to the manufacturers' prescribing information and/or instructions for use for the indications, contraindications, warnings, and precautions associated with the medications and devices referenced in these materials.

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