Living Your Best Life With Advanced Heart Failure
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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 Society please visit our web site 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.
Introduction

Heart failure is a chronic (lifelong) condition that must be treated. But with proper treatment, you can live a full life with heart failure. You can feel better, reduce your chance of going into or being readmitted to the hospital, and live longer by taking care of yourself.

Thanks to recent advances in medical treatment, the symptoms of heart failure can be relieved and the progress of heart failure can be slowed, stopped, and in some cases even reversed. Still, the progress of heart failure is different for each person, so it can be hard to predict what the future holds. That’s why it’s important to prepare for the times ahead, when you may feel ill or require someone else to make decisions about your medical care. Later in this guide, we’ll provide you information designed to help ease the process of preparing an advance care plan, including the documents you’ll need.

But first, let’s review some of the basics of heart failure.

The Types of Heart Failure

There are three basic types of heart failure:

1. Left-sided systolic failure, in which the left ventricle can’t contract as it should.
2. Left-sided diastolic failure, in which the left ventricle can’t relax the way it should.
3. Right-sided heart failure, in which the right ventricle can’t contract as it should.

The treatment you’ll receive depends in part on the type(s) of heart failure you have.
Stages of Heart Failure

To decide how to treat your heart failure, your doctor will likely refer to the stage your condition has reached. This is determined by the New York Heart Association’s Functional Classification. Heart failure is classified both by symptoms and by stage. The tables below outline the classifications of heart failure according to these standards.

<table>
<thead>
<tr>
<th>Class</th>
<th>Symptoms You May Experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Your physical activity is not limited. Ordinary physical activity does not cause you undue fatigue, palpitation, or dyspnea (shortness of breath).</td>
</tr>
<tr>
<td>II</td>
<td>There is a slight limitation of your physical activity. You’re comfortable at rest. Ordinary physical activity results in fatigue, palpitation, dyspnea (shortness of breath) for you.</td>
</tr>
<tr>
<td>III</td>
<td>There is a marked limitation of your physical activity. You are comfortable at rest. Less than ordinary activity causes fatigue, palpitation, or dyspnea for you.</td>
</tr>
<tr>
<td>IV</td>
<td>You are unable to carry on any physical activity without discomfort. You have symptoms of heart failure at rest. If you engage in physical activity, discomfort increases.</td>
</tr>
</tbody>
</table>

Stages of heart failure

<table>
<thead>
<tr>
<th>A</th>
<th>You have risk factors for heart failure but no changes in your heart or symptoms.</th>
</tr>
</thead>
<tbody>
<tr>
<td>B</td>
<td>You have structural changes in your heart but you have never had heart failure symptoms</td>
</tr>
<tr>
<td>C</td>
<td>You have structural changes and you have experienced symptoms</td>
</tr>
<tr>
<td>D</td>
<td>You have advanced heart failure and need aggressive medical therapy</td>
</tr>
</tbody>
</table>
Managing Medications and Treatments

Thanks to effective medications and other treatments, people with heart failure can now live full lives.

Medications

It’s important to be aware of what your medications are, how they work, and when and how to take them. You will take a combination of some of the medications commonly used to treat heart failure:

- **Angiotensin-converting enzyme (ACE) inhibitors**: These drugs are a type of vasodilator, which work to relax blood vessels and lower blood pressure. By doing that, they improve the flow of blood through the body and decrease the amount of work the heart has to do.

- **Angiotensin II receptor blockers (ARBs)**: These drugs work in much the same way as ACE inhibitors. They are often prescribed for people who can’t tolerate the side effects of ACE inhibitors.

- **Angiotensin-receptor/neprilysin inhibitors (ARNIs)**: This new class of heart failure drugs combines a drug that blocks a specific enzyme with an ARB. They lower blood pressure and decrease strain on the heart. This drug should not be taken by patients who are using ACE inhibitors or by patients who have or had angioedema (serious allergic reactions with hives).

- **Beta blockers**: These drugs slow the heart rate and reduce blood pressure. In some cases, they can induce improvement in heart function.

- **Diuretics**: Also known as water pills, these drugs cause you to urinate more often and prevent fluid from collecting in your body. The body tends to lose potassium and magnesium as a result of more frequent urination, so your doctor may prescribe mineral supplements to replace what you lose.

- **Aldosterone antagonists**: This type of drug is known as a potassium-sparing diuretic. They can raise the level of potassium to very high levels, so your doctor may advise you to reduce your intake of foods containing potassium.

- **Inotropes**: For some people with severe heart failure, these intravenous (IV) drugs help improve the heart’s pumping and maintain blood pressure. They are given to people who are in the hospital.

- **Isosorbide dinitrate/hydralazine**: This drug contains two vasodilators and specifically helps African Americans with heart failure.
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- **Digoxin (digitalis):** This drug increases the strength of your heart’s contractions and slows the heartbeat.

- **Sinoatrial node modulator (ivabradine):** This new class of drugs is used with beta blockers when they cannot lower your heart rate enough. It helps reduce the amount of oxygen your heart needs and the amount of work your heart must do.

Keep in mind that while you will likely receive a combination of medications, not all will apply to you. Your doctor will prescribe the medications that make the most sense for you, given the symptoms of heart failure you are experiencing and the stage you’re at. Regardless of what drugs you’re prescribed, it’s very important that you take them exactly as your doctor instructs you to. You can find those instructions on the bottle itself or in the patient information that comes with the drug. You should take them at the right time every day and with the right food or drink, as your doctor instructs. Note any limitations that you should observe while taking the drugs. Also, be sure to get refills well before you run out so you don’t miss a dose.

If you have any side effects or any questions about your medications, talk with your doctor. He or she may have you adjust your dosage or try a different drug.

Also, talk with your health care provider before taking any other medications or dietary supplements. Some of these (such as ibuprofen and naproxen, which are often used for aches and pains) can make your heart failure worse.

Remember that the drugs can’t work the way they should if you don’t take them the way your healthcare provider or pharmacist has instructed you to take them.
Devices

Sometimes more help is needed to address some of the symptoms of heart failure. This is especially true when problems with the ways the heart beats (also known as irregular heartbeats, or arrhythmias) are an issue. In many such cases, an implanted surgical device may be the answer. Most common are:

- **Implantable cardioverter defibrillator (ICD):** An ICD is like a pacemaker but is implanted just under the skin in your chest. It has wires that connect through your veins into your heart. ICDs can speed up the heart rate if it’s beating too slow, and can correct dangerous heart rhythms by shocking the heart back to normal. ICDs are sometimes used along with pacemakers to keep the heart beating as normally as possible.

- **Cardiac resynchronization therapy (CRT):** This small device is implanted just below the collarbone. It helps the heart pump better by sending electrical signals to the heart’s lower chambers, so they beat together the way they’re supposed to.

Procedures and Surgeries

Surgery and other procedures are sometimes required to correct some underlying problems that may have led to heart failure. These procedures do not necessarily reverse the effects of heart failure or cure the condition, but they help protect your heart. They include:

- **Coronary stents:** In some patients with heart failure, narrowing of the arteries to the heart causes a reduction in blood flow to the heart. In these cases, a stent can be placed during a cardiac catheterization procedure (in which a tube called a catheter is inserted through an artery in your groin or other area and into the blocked artery) to open the blockage and improve blood flow.

- **Coronary bypass surgery (CABG):** When the artery blockages are too complex for stents to be placed, open heart surgery may be required. In this procedure, blood vessels from your leg, arm, or chest are removed and then surgically implanted near the site of the blockage to bypass the blocked area of the artery. This allows blood to move the way it should to your heart.

- **Heart valve surgery:** Heart failure is sometimes caused by a faulty heart valve. When that’s the case, surgery to correct the faulty valve (through repair or replacement) may be recommended. When a valve can’t be repaired, it is replaced by an artificial valve.
Cardiac Rehabilitation

Many people with heart failure find that cardiac rehabilitation provides both a supervised fitness program and a support system that helps them make healthy lifestyle changes for managing their condition. It can also help patients improve their health outcomes, such as staying out of the hospital. Talk with your doctor about the availability of a cardiac rehab program where you live. Many insurance companies now cover it.

Clinical Trials

Some heart failure does not have good treatment options. If you have this condition, you may want to consider enrolling in clinical trials to help find effective treatments.

Curious about how Clinical Trials work? Check out our Module 11
Managing Your Lifestyle

Making positive lifestyle changes is almost always necessary for people with heart failure. This often includes changing your diet, getting more physical activity into your day, and quitting if you smoke.

Diet

Eating a healthy diet is a vital part of the treatment plan. Your doctor will work with you to help you understand what you need to do to adopt a healthier diet. These tips are often prescribed:

- **Eat less salt (sodium).** Sodium retains water in the body. That can cause your heart to work harder and contribute to edema and shortness of breath. Sodium intake is often limited to 2,000 mg per day. Your doctor will recommend a limit to your sodium intake. It’s important that you stick with that number. Be on the lookout for “hidden” salt in processed and prepared foods, which often have salt added to them. Reading food labels can help you determine how much salt you’re eating every day. When eating out, ask your server for nutritional information on the dishes you want to order. At home, herbs, lemon juice, and spices can add lots of flavor to recipes and help you limit salt.

- **Limit alcohol and fluids if instructed to do so.** Alcohol can weaken the heart muscle and increases the risk of heart rhythm problems. Your doctor will advise you how much fluid you should drink each day.

- **Eat lean meats and poultry.** Avoid adding salt, saturated fat, or cholesterol to the recipe. Also, watch your portion sizes. You want to keep the serving at 4 to 6 ounces—about the size of your fist.

- **Eat oily fish (salmon, trout, herring) at least twice a week.** These types of fish contain omega-3 fatty acids, which can help reduce the risk of coronary artery disease.

- **Avoid processed and prepared foods.** These can be high in sodium and tend to have saturated or trans fats in them.

- **When dining out, request little or no salt be added to the dish.** Choose baked or steamed dishes, when possible, over fried options.

Physical Activity

Exercise is critical for people with heart failure. However, talk with your doctor about how often and when to exercise. He or she may recommend you avoid physical activity on days when fluid has built up and you don’t feel well. Your doctor can help you make a plan for when and how often you should exercise. Pace yourself, pay attention to how you feel, and rest.
Living Your Best Life With Advanced Heart Failure
Taking Control of Heart Failure

when you get tired. Most people should aim to get at least 30 minutes of physical activity per day, most days of the week. Better still, try to exercise every day.

Keep in mind that you don’t have to get all 30 minutes at once. It’s just as good for you to break exercise into 5- to 10-minute segments. Plus, there are other ways to add physical activity to your day. Consider:

■ Going out for a walk. Take the dog with you, and invite friends and family members to join you.
■ Parking your car farther from your destination and taking a walk to get you there.
■ Walking instead of driving, when feasible.
■ Getting off the bus or subway a stop or two earlier than you usually do and walking the rest of the way.

Smoking
Smoking is terrible for your health no matter what your condition is. Smoking has been directly linked to heart disease, cancer, stroke, and other serious conditions. It’s not easy to quit smoking, but it can be done—and there are more tools to help you do just that than ever before. Talk with your doctor about treatments and support groups that are available to you to help you quit.

Many people who quit smoking find that support is a huge help. Talk with your family and friends about helping you quit. One tool that may help is the Quit Line: 1-800-QUIT-NOW. Another is the American Lung Association’s Freedom From Smoking program, available at www.ffsonline.org.

Stress
Dealing with too much stress can make many health conditions worse, including heart failure. But you can keep stress at bay by exercising (a great stress reliever) and taking time to relax. Consider:

■ Enjoying your favorite hobbies
■ Spending time with friends or family
■ Doing deep-breathing exercises
■ Practicing yoga or tai chi
■ Taking a nap
■ Reading a book
■ Listening to music
■ Taking a warm bath

There are many ways to relax—those listed above are just a few ideas.
Getting Support

As heart failure progresses, it can become isolating for the person who has it. But it doesn’t have to be. Doing everything you can to manage your health is important. But so is getting support when and where you need it.

Talk with your healthcare provider about support options available to you. There may be heart failure support groups meeting in your area. These can be good sources of encouragement and information for people with heart failure. Your local hospitals may also offer support groups.

Check out online message boards for an additional support source. The American Heart Association offers one at supportnetwork.heart.org/heart-failure. There are others, as well. Do an Internet search for “heart failure support groups” and explore the options available to you.
Staying Safe

As we age, safety becomes even more important. Taking precautions is a good idea for avoiding accidents. Consider:

- A medical alert or some other system for emergency contact
- Keeping all emergency contact phone numbers in a prominent place, such as your refrigerator door
- Installing a fire extinguisher and smoke detector on every floor of your home
- Never smoking when alone or in bed
- Arising slowly after sitting or lying down, making sure you are well-balanced
- Wearing shoes that fit
- Using a walking aid, if needed. Make sure it is correctly measured by a professional.
- Taping down or removing all area rugs
- Hiding electrical and telephone cords from high-traffic areas
- Not using slippery wax on floors
- Wiping up all spills immediately
- Avoiding standing at heights, using ladders or chairs
- Installing sturdy rails for all inside and outside stairs, or purchasing a stairlift if needed
- Using non-glare incandescent light bulbs of 100 watts or more, or their fluorescent equivalents
- Making sure there is good lighting in all stair cases
- Making sure that all steps have a non-slip surface

One of the hazards of aging regardless of one’s health condition is falling. Falls can be very serious. They can lead to fractures and broken bones, concussions, and more.
There are steps you can take to help prevent falls at home, though. These include:

- Using a cane or walker
- Wearing slip-resistant, low-heeled rubber-soled shoes
- Avoiding sidewalks when they're slick
- Putting salt or kitty litter on iced-over sidewalks
- Keeping clutter out of rooms and off floors
- Using carpet runners
- Avoiding walking in socks, stockings, or slippers
- Installing grab-bars on bathroom walls near the tub, shower, and toilet
- Putting a nonskid bathmat in the shower or tub
- Keeping a flashlight near your bed
- Placing more lighting in rooms
- Keeping a cell phone so it’s with you at all times

There are a number of devices that can help you stay safe in the home and elsewhere. These include a stool for the shower, wheelchair, scooter, home oxygen, or a ramp that covers the stairs.
Getting the Most Out of Life

No matter what your health condition is, making the most of your days is key to relishing the time you have. Do you know what sorts of activities make you happy? If so, enjoy them to the fullest. If not, or if you’re not sure, try something new to see what you think. Every activity we take pleasure in starts with a first step into the “unknown.”

To find new activities you might enjoy, consider:

- What you already enjoy
- What you have an interest in, but have never tried
- What your friends and family do for fun
- What’s available in your area

Trying something new isn’t easy, but once you get over the uncertainty, you may find yourself enjoying a new activity. If you don’t enjoy the new activity, try another one. You’ll find something you like soon enough. And don’t neglect the “old” activities that still give you pleasure.

Take time to enjoy your relationships with family and friends. Staying socially active and connected to your love ones is great for your mental and spiritual health.

Of course, you should work with your health care team every step of the way to make sure your treatment program is doing what it should. Living independently for as long as you can will go a long way toward helping you get the most out of life.
Living Your Best Life With Advanced Heart Failure
Caregiving

Caregivers of people with heart failure have a lot of responsibilities to tend to. It’s not hard to get overwhelmed with the care of a loved one if you’re not careful. But there are steps you can take, and sources of support, to help you manage.

Remind yourself that you can’t take care of someone else unless you take care of yourself. It’s easy to let self-care lapse when you’re taking care of a loved one with a chronic health condition, like heart failure. But that’s an easy path to burnout. Burned-out caregivers can’t provide the level of care they’d like.

Taking care of yourself means eating a healthy diet, getting plenty of exercise, keeping stress at bay, and dealing with difficult emotions. It’s not easy to do these things when you spend so much time caring for a loved one, but it’s very important that you make time for these needs. One way to do this is to create a caregiving support team. This team can be made up of family members and friends. Their role is to relieve you of your duties for a little while so you can tend to your own needs. And yes, sometimes that means time for you to get out of the house and enjoy a social life.

Another important avenue of support is a support group. Ask your doctor if there are any caregiver support groups available in your area. Check with your local government agency for the aging to see if they offer anything. Check online for heart failure discussion forums that can also provide support.

Managing your emotions is also key to maintaining your health while providing care. Everyone deals with sad or restless feelings from time to time. It’s when these become more intense and last longer that they can become a concern. Anxiety and depression are serious medical conditions that should be treated. Fortunately, there are very effective treatments for both conditions. Talk with your doctor if you think you may be dealing with anxiety and/or depression.
The Symptoms of Depression

The signs that you may be dealing with depression include:

- Having a hard time concentrating, remembering details, or making decisions
- Feeling tired often
- Feeling guilty, worthless, or helpless
- Feeling hopeless or pessimistic
- Insomnia or excess sleeping
- Feeling irritable or restless
- Losing interest in enjoyable hobbies or activities, including sex
- Losing appetite or overeating
- Aches, pains, headaches, cramps, or digestive problems that do not go away, even with treatment
- Sad, anxious, or “empty” feelings that do not go away
- Thinking about or attempting suicide
The Symptoms of Anxiety

The signs that you may be dealing with anxiety include:

- Feeling panic, fear, or uneasiness
- Having trouble sleeping
- Cold or sweaty hands or feet
- Shortness of breath
- Heart palpitations (rapid or violent heartbeats)
- Feeling fidgety or antsy
- Dry mouth
- Numb or tingling hands or feet
- Nausea
- Muscle tension
- Feeling dizzy

One of the most challenging aspects of caregiving is knowing when to ask for a second opinion on your loved one’s treatment plan. Remember, it is your loved one’s right as a patient to seek a second opinion if anything about his or her treatment plan seems risky or unclear; if the patient is considering joining a clinical trial for a new drug; or if you’re considering a new, experimental treatment. As the caregiver, you have the right to be there every step of the way in your loved one’s treatment for heart failure.

When you believe a second opinion is called for, neither the caregiver nor the patient should be shy about requesting it. Select a doctor outside of the primary doctor’s practice to reduce the pressure to conform to the first opinion.
Making an Advance Care Plan

An advance care plan is a written document that ensures that the medical care you receive meets your preferences and health needs. It should also weigh your social, cultural, and religious requirements. Planning can help reduce stress and ease concerns about future care options.

Keep in mind that an advance care plan does not guarantee that your instructions will be followed, but it does increase the possibility that they will.

Advance care plans cover such issues as:

- Whether you want to be resuscitated (revived if your heart stops beating)
- Whether you want to have a mechanical ventilator breathe for you if needed
- How you want your pain relieved if that becomes an issue
- How other medical problems and complications should be handled if they occur

It’s important that your advance care plan complies with your state’s legal requirements, so your health care team can follow it.

An advance care plan includes:

- An advance care directive
- A do-not-resuscitate order
- A living will
- A power of attorney
- A financial plan

There are many attorneys who are elder-law and estate-planning specialists. They can help you prepare these documents if you think you need expert guidance.
Living Your Best Life With Advanced Heart Failure
Advance Care Directive

This document provides guidance about your future medical care. It typically includes a living will, a durable health care power of attorney, and a statement about organ donation.

A federal law requires hospitals and other health care providers that participate in the Medicare and Medicaid programs to give all patients written information about their rights to make advance directives and accept or refuse medical care or surgical treatment.

Do-Not-Resuscitate Order

This is a type of advance care directive that tells doctors, nurses, and emergency personnel what they should and should not do when the person stops breathing or when their heart beats with dangerous irregularity or stops entirely. A do-not-resuscitate order is written by the patient or his/her family as they consult with their doctor.

A do-not-resuscitate order can include specific instructions on whether to use different methods to revive a person, including:

- **Cardiopulmonary resuscitation (CPR):** Manual chest pressure and mouth-to-mouth breathing to circulate blood and give oxygen to the lungs
- **Defibrillation:** An electric shock to the heart to restore a normal heart beat
- **Breathing tube and machine:** A device that aids breathing
- **Medicines:** Used to restore an effective heart rate and improve blood circulation to the major organs

Living Will

This legal document expresses the wishes about life-sustaining medical treatment of the patient should that person become unable to communicate. It’s often used when the patient is terminally ill, which means that the person has a chronic (lifelong) condition that is irreversible and has no reasonable chance of recovery.

Health care providers rely on living wills to guide their efforts within the patient’s own specified limits. Your limits may include the use of medical therapies to treat your condition, including CPR, blood transfusions, mechanical breathing, surgery, antibiotics, kidney dialysis, and invasive approaches to providing nutrition and fluids.
As with advance care directives, state laws regulate what a living will can specify. It’s a good idea to contact a lawyer in order to prepare one.

**Health Care Power of Attorney**

This document allows someone to make all the health care decisions on your behalf if you are unable to make decisions for yourself. The person whom you designate to make these decisions will be guided by your living will, so it’s important to have that document ready as well. The person with health care power of attorney has the authority to interpret your living will if there are questions about it and to make health care decisions that he or she believes are in your best interest.

A health care power of attorney can be as limited or as broad in scope as you choose to make it. They typically cover specific treatments, such as tube feeding, intravenous fluids, and organ donation if you haven’t covered those in your living will.

A “durable” health care power of attorney is one that legally allows the authorized person to make decisions for you even if you become incapacitated.

Again, state laws regulate what health care power of attorneys can say, so consulting an elder-care or estate-planning lawyer is a good idea.

**Financial Planning**

One concern that nearly all heart failure patients and their families face is how to pay for the treatment and other medical needs. It’s a good idea to talk with your doctor or nurse if you have these concerns. They often know about ways to help you pay for medicines and other health care bills. Hospitals often have social workers who are skilled in this area, as well.

Many drug companies offer programs to help low-income patients afford their medicines. They usually require filling out specific forms, which your doctor or nurse will need to help you with.
Discussing Your Wishes

It’s never easy to talk about the end of life with family and friends. But it’s important to do so. Having a plan in place makes the difficult decisions that must often be made regarding a loved one’s care much clearer.

You can start the conversation by sharing with your loved ones your desire to discuss the issues:

- “I’d like to talk about the help we will need as my heart failure gets worse.”
- “We need to talk about what kind of support is available once I become unable to take care of myself.”
- “Let’s discuss what we can do to help make my life easier.”
- “I want to talk about what you should do in case of an emergency, especially if it involves cardiac arrest.”
- “I have been more tired recently than I was in the past. Let’s talk about what can be done to help me feel better.”

What other ways are there to introduce the topic? Write down your ideas here:

Ideas

________________________________________________________________________

________________________________________________________________________

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Living Your Best Life With Advanced Heart Failure
Talking With Your Doctor or Nurse

You need accurate information about heart failure, especially your specific condition, to make good decisions about end-of-life care. Talking with your doctor or nurse is the best way to get that information.

One issue that needs to be discussed is palliative care. This is health care that does not seek to cure a disease, but to soothe, prevent, reduce, or relieve symptoms. Sometimes palliative care also includes treatments to help you reach personal goals, get meaning out of everyday life, and overcome any conflicts you face with end-of-life considerations.

Here are some questions to consider asking:

■ How quickly is my heart failure progressing?
■ Is my heart failure still responding to drugs?
■ What else can help me if my heart failure stops responding to therapy?
■ What can I be doing to improve the quality and length of my life?
■ Is there a palliative medical team you routinely work with?
■ When is the right time to get the palliative care team involved with my care?
■ How can I tell when my heart’s condition is getting worse? Are there signs or symptoms I should expect?
■ If I am going to the hospital often for my heart failure, does that mean it’s getting worse? Do I need to think about end-of-life issues now?

Just as you have questions, your doctor or nurse may have questions for you. The goal of these questions is to determine what course of treatment is best for you. They may ask:

■ What does heart failure mean to you?
■ What does “quality of life” mean to you?
■ What are your hopes for the future?
■ What are your fears? What are you most afraid of, if anything?
■ What would remain to be done if you were to die today?
■ Have there been times in your life when faith was important to you?
■ What has given you the most meaning in your life?
■ Might there be a time when it would not be worth it to stay alive?
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- Which heart failure symptoms bother you the most?
- Is heart failure causing practical problems for you? If so, what?
- How do you treat your heart failure symptoms?
- What do you rely upon (person, place, or thing) to help you feel better?
- Have you lost family members or other loved ones? What was that like for you?
- Are there family members or other loved ones who need to know what is going on?

Answering these questions may help prepare you for discussions about advance care planning.

A Second Opinion

So what’s the best treatment plan for you? Your doctor and health care team will work with you to make those decisions. Consider also that not every insurance company covers treatments for every form of heart failure. Find out if your insurance provider covers your particular type.

One of the most challenging aspects of getting the right treatment plan is knowing when to ask for a second opinion. Remember, it is your right as a patient to seek a second opinion if anything about your treatment plan seems risky or unclear; if you are considering joining a clinical trial for a new drug; or if you’re considering a new, experimental treatment.

When you believe a second opinion is called for, don’t be shy about requesting it. Select a doctor outside of the primary doctor’s practice to reduce the pressure to conform to the first opinion.
Making Care Choices
Among the things people worry about as heart failure progresses are burdening their families and dying in pain. Being told “nothing more can be done” does not mean that their doctor or hospital will stop caring for them. Every heart failure patient is entitled to be cared for and have their pain managed, regardless of what heart failure stage they’re at.

Also, you can choose how and where you’ll be cared for as your heart failure progresses. Some people prefer home-based care and to die at home when that time comes. Others prefer the care of a hospital.

Palliative Care
You may have heard the term “palliative care.” This means medical care that is designed to improve the comfort and quality of life of patients and their families when they are faced with a life-threatening or terminal chronic illness. The course of heart failure is not always predictable, so this type of program does not have the same entry requirements as a hospice program, which usually requires patients to have 6 months’ or less life expectancy.

Palliative care programs, like hospice programs, are not designed to cure the life-threatening condition. They try to individualize health care to a person’s individual physical, social, spiritual, and psychological needs. Patient education is often part of the care plan and usually covers ways to decrease shortness of breath, conserve energy for activities that matter most to you, and monitor your condition.
Hospice Care

As previously mentioned, hospice care programs provide medical and support services to patients expected to be in their last 6 months of life. Hospice care is provided 24 hours per day, 7 days per week, and can be provided in a hospice unit, a nursing home, or in the patient’s home. It generally follows these guidelines:

■ The goal of care is to provide comfort, rather than cure the patient.
■ Relieving pain and controlling symptoms—by any means necessary—are tailored to the patient’s needs and desires.
■ The patient’s family takes part in the care program.
■ The patient and family set the agenda for day-to-day care.
■ The palliative care team can include nurses, volunteers, chaplains, therapists, bereavement counselors, social workers, and doctors.
■ There is a spiritual aspect to the care program that is not specific to any religion or faith. This part of the palliative care program is aimed at helping patients understand and reconcile the meaning of their final days.
■ The program may provide long-term bereavement support for family and friends.

Home Health Care

No matter what course you choose, you will likely feel more tired and short of breath as your condition progresses. One possible approach to your treatment may be to receive nursing care at home.

A home health care nurse can monitor your vital signs, weight, heart failure status, blood laboratory work, and medication dosing. This nurse may also administer intravenous medications there to decrease discomfort, pain, or difficulty breathing, and prevent hospitalization.

Other Supportive Care

Occupational therapists, respiratory therapists, and physical therapists may also be part of your treatment plan. They can help you move and breathe more easily, and keep your muscles conditioned so that movement causes you fewer aches and pains. They can also help you get equipment to assist you in your day-to-day activities.
Securing Your Advance Care Plan

Once you have your advance care plan documents ready, it’s wise to make copies of your living will, DNR order, health care power of attorney, and any other directions about your medical care decisions and give copies to your health care team. Your doctor and/or the hospital will keep these copies on file so they have easy access to them when they’re needed. You’ll also want to give a copy of the health care power of attorney to the person you have designated.

It’s also a good idea to carry a wallet card that states that you have advance care directive documents and whom to contact to find those.

Review your advance care plan every few years to make sure it still reflects your wishes and meets current legal requirements. If you change your mind (which is common), you can change or cancel any of the documents you have prepared. If you do so, be sure to alert your family and health care team that you have done so and provide updated documents as needed.

Resources

There are many good sources of information and tools you can use to help you navigate your way through heart failure.

- The American Heart Association has a complete caregiver information page with many resources available. Go to [www.heart.org](http://www.heart.org) and click on “Support,” then “Complete Caregiver Resources.”
- The Mended Hearts, Inc., is a volunteer organization made up of heart-event survivors who provide peer assistance to those living with heart conditions. They offer caregiver resources at mendedhearts.org/education.
## Checklist for Life
Tear this checklist from the booklet and carry it with you

<table>
<thead>
<tr>
<th>What everyone needs to do</th>
<th>What everyone needs to do</th>
<th>Staying Vibrant, Staying Safe</th>
</tr>
</thead>
<tbody>
<tr>
<td>■ Checklist for life</td>
<td>■ Finding hope</td>
<td>■ Building strength</td>
</tr>
<tr>
<td>■ Know my treatment</td>
<td>■ Identifying joy</td>
<td>■ Where I live</td>
</tr>
</tbody>
</table>

### Checklist for life

<table>
<thead>
<tr>
<th><strong>Finances</strong></th>
<th><strong>Answer</strong></th>
<th><strong>Date</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Make a list bank accounts</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Make a list of assets</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Wills</strong></th>
<th><strong>Answer</strong></th>
<th><strong>Date</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Estate will</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living will</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health care Power of Attorney</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial Power of Attorney</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Advanced Directives</strong></th>
<th><strong>Answer</strong></th>
<th><strong>Date</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you want to be resuscitated?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Funeral preparations</strong></th>
<th><strong>Answer</strong></th>
<th><strong>Date</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you want to be buried?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to be cremated?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a burial site?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a funeral home preference?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want a religious service?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have special wishes for visitation?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Talk to your family/friends</strong></th>
<th><strong>Answer</strong></th>
<th><strong>Date</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Do they understand your medical condition?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do they know your wishes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a designated family member or friend that is willing to assist with medications and doctor visits when and if needed?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I want to have fun!</td>
<td>Answer</td>
<td>Date</td>
</tr>
<tr>
<td>---------------------------------------------------------</td>
<td>--------</td>
<td>------</td>
</tr>
<tr>
<td>What makes you happy?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What makes you smile?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>What is important to you?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Define a reasonable goal and make it happen!</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Share memories with family and friends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to travel?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to go fishing?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to visit family of friends?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to put your toes in the sand?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you have a project to finish?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you want to make contact with a religious professional?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Staying Vibrant - Staying Safe</th>
<th>Action</th>
<th>Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Building strength</strong></td>
<td>Exercise – walk, take more steps</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Good nutrition</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Memory and thinking</td>
<td></td>
</tr>
<tr>
<td><strong>Where I live…</strong></td>
<td>Do I love it?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do I need it?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Can I leave it?</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Shifting needs—where could I live?</td>
<td></td>
</tr>
<tr>
<td><strong>Planning help</strong></td>
<td>For the future—Identify a care supporter</td>
<td></td>
</tr>
<tr>
<td><strong>Staying independent:</strong></td>
<td>Do you need a devices to maintain freedom and independence - ex: cane, wheelchair, walkers</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Do you need to redefine your self-image? Perhaps you cannot do everything that you used to – but that’s okay!</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Prevent falls - ex: hold onto railings, removed objects that you could cause you to trip</td>
<td></td>
</tr>
</tbody>
</table>
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:

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________

_________________________________________________________________
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.

Made possible with support from the HFSA Quality Care Program, Amgen, Bayer, and Abbott