Module 9

Advance Care Planning

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 code:

Phone number:

Fax:

E-mail:

Other Important Phone Numbers:

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

Pharmacy:

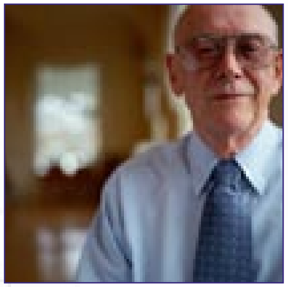
Other doctors or nurses:

Introduction

Heart failure is a serious chronic condition that can shorten your life. With proper management and active self-care, you can feel better, decrease your chances of being in the hospital, and live longer. Advances in treatment can slow, stop, or in some cases reverse the progression of heart failure. However, even with the best medical care, heart failure may progress over time. The progress of heart failure is unpredictable and different for each person, so you may feel uncertain about what to expect in the future. Therefore, it is important for you and your family to talk about how you want to be cared for in the future should you become very ill and unable to make decisions about your medical care. One way to plan for such a possibility is to make an advance care plan.

Making an advance care plan can ease worries about what might happen to you if you are unable to make decisions about your own care or about death and dying. Getting answers to your questions and letting people know what you want at the end of your life can help you feel more in control and give you peace of mind as you go about living your life. An advance care plan is a good idea for all adults, regardless of their medical history.

This module will discuss topics related to advance care planning that you can think about and talk over with your family. There are no right or wrong decisions on these topics, so you can be open and honest about your feelings and make choices that are best for you.



Introduction

This module will provide information on:

- Advance care plan components.
- The importance of an advance care plan.
- Making an advance care plan.
- What to do with your advance care plan.
- Care choices.
- Changing your mind.

It will help you:

- Understand the purpose of an advance care plan.
- Make your own advance care plan.
- Understand what to do with your advance care plan.
- Involve your family, friends, health care providers, and other advisors such as a lawyer in your plans for future medical care.

What Is an Advance Care Plan?

An advance care plan is a written document that helps you to ensure that your care is customized to reflect your personal preferences and health needs, as well as meet your social, cultural, and religious requirements. It covers issues such as whether you want to be resuscitated (revived if your heart stops beating) or whether you want to have a mechanical ventilator breathe for you if needed. You can also specify how you want pain relieved if it develops and talk about how other medical problems and complications should be handled if they occur. An advance care plan does not guarantee that your instructions will be followed, but it does substantially increase the likelihood. Making sure that your advance care plan conforms to any legal requirements in your state helps ensure that your health care providers will comply with it.

Even if you do not create a written advance care plan, it is important to let your health care providers, family, and other caretakers know about your wishes regarding future medical care.

Importance of an Advance Care Plan

Telling people what you want helps them care for you in a way that best meets your wishes. It may also increase communication about end-of-life needs and concerns and make life less stressful for you. Knowing that you have made arrangements for your care may even improve your outlook for the future. It can also make it easier for your family to make decisions about your care.

Advance Care Plan Components

An advance care plan can consist of any number of written documents including:

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

These documents are discussed in more detail in the following sections. Your doctor, nurse, or hospital can give you information and written materials about advance care planning. Many agencies on aging, state and national bar associations, and medical societies may also be good sources of information.

You may wish to use a lawyer with experience in estate planning or elder care to help you prepare an advance care plan to ensure that it meets your individual wishes and state legal requirements.

Advance Care Directive

You or another person that you specify can provide guidance about your future medical care in a document called an advance care directive. An advance care directive should provide clear evidence of your wishes regarding treatment and can include a living will, a durable health care power of attorney, and a statement about organ donation.

A U.S. federal law called the Patient Self-Determination Act requires hospitals, nursing facilities, hospices, home health agencies, and other health care providers participating in the Medicare and Medicaid programs to give all patients written information about their rights to accept or refuse medical or surgical treatment and to make advance directives.

Advance Care Plan Components

Do-Not-Resuscitate Order

A do-not-resuscitate order is a type of advance care directive that tells doctors, nurses, and other rescue personnel what they should or should not do when a person stops breathing or when their heart beats so irregularly as to threaten life or stops entirely. The decision to have a do-not-resuscitate order is made by the patient or his/her family in consultation with the doctor.

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

- Cardiopulmonary resuscitation (CPR) – Manual chest pressure and mouth-to-mouth breathing to circulate blood and oxygenate the lungs.
- Defibrillation – Delivering an electrical shock to the heart to restore a normal heart beat.
- Breathing tube and machine – Used to assist with breathing.
- Medicines – Given to restore an effective heart rate and improve circulation of blood to major organs.

Living Will

A living will is a legal document that lets a person who is unable to participate in decisions about their medical care express their wishes about life-sustaining treatment. A living will is usually used during a terminal illness when a person is unable to communicate. A terminal illness is one in which death is expected to occur with or without medical intervention and also applies to an irreversible condition, when there is no reasonable chance for recovery.

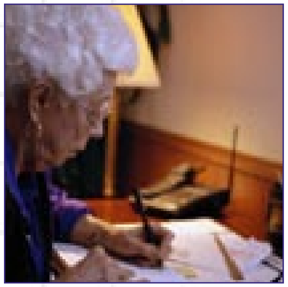
A living will guides health care providers and allows the patient to set limits on what is done to them. You can personalize your living will by including specific statements about the use of medical treatments which may apply to your condition, including CPR, blood transfusions, mechanical breathing, surgery, antibiotics, kidney dialysis, and invasive measures to provide nutrition and fluids. State laws vary in their requirements for living wills, so it is advisable to contact a lawyer to make a living will that is valid in your state.

Advance Care Plan Components

Health Care Power of Attorney

A power of attorney lets another person make legally binding decisions for you. A health care power of attorney lets someone make all health care decisions for you including the decision to refuse life-sustaining treatment if you are unable to make the decision for yourself. If you have a living will, the person with a power of attorney also has the authority to interpret your living will in the event there are questions about it and make decisions that he or she believes to be in your best interest.

You can give someone a general power of attorney to make decisions for you or you can limit their decision-making to certain issues by including instructions about your care. For example, you can specify preferences regarding particular treatments such as tube feeding, intravenous fluids, and organ donation, to the extent you have not already covered those subjects in a living will.



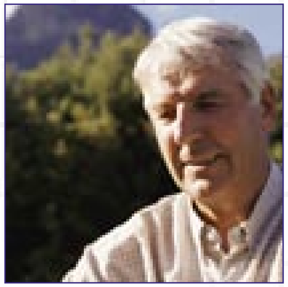
If the power of attorney is a "durable" power of attorney this means that the person authorized to make your health care decisions can make them even after you become incapacitated. Having a durable health care power of attorney helps ensure that the specific person you want to make decisions for you, such as a family member, will have the legal right to act on your behalf.

While state laws vary, in general, the paperwork granting someone any type of power of attorney must be signed voluntarily and be witnessed by a notary public. A power of attorney must be completed when you are still capable (competent) of making decisions and before you become terminally ill. To ensure that a power of attorney complies with the laws in your state, it is advisable to consult with a lawyer who has experience in that area of law and can verify who may or may not serve as a health care power of attorney.

Financial Planning

Heart failure can be expensive to treat. You and your family may have concerns about paying for medicines, doctor and hospital bills, and other types of health care. If paying for care is a worry for you and your family, talk with your doctor or nurse. They can often help you find ways to pay for medicines, and other health care bills. Many hospitals or clinics also have social workers that can help with these issues.

Some drug companies have programs that provide medicines free to low-income patients if a doctor or nurse fills out special forms. Do not be shy about applying for these programs if you meet the criteria. The programs are there to help people get the medicines they need.



Getting Started on an Advance Care Plan

As part of responsible planning for the future, everyone should make an advance care plan. While it may be difficult to discuss death and dying with family and friends, everyone benefits from knowing your wishes. Your family and friends may want to know what you are feeling and thinking but may be afraid to ask you. It might be easier if you bring the topic up first. For example, you can trigger a meaningful discussion by saying:

- "I'd like to talk about what you should do in the event of an emergency, especially one involving a cardiac arrest."
- "It seems like I am more tired than I have been in the past. I'd like to talk about what can be done to make me feel better."
- "Let's talk about what we can do to make my life easier."
- "I'd like to talk about the help we will need as my heart failure worsens."
- "We should explore what kind of support is available when I can no longer take care of myself."

Topics to Discuss with Family or Friends

Questions for Your Doctor or Nurse

Communication is an important part of advance care planning and end-of-life care. (End-of -life is considered the final weeks of life when death is near.) As you begin to develop an advance care plan, it is important to have accurate information about heart failure and the specifics of your condition, so that you know what might be involved in your care. To get the most up-to-date information, you should talk to your doctor or nurse and other members of your heart failure team. You may wish to ask the following questions during your discussion:

- Is my heart failure progressing slowly or rapidly?
- Is my heart failure still responding to medications?
- Is there anything else that can help me, when my heart failure no longer responds to my current therapy?
- Are there things I can be doing better or more of to improve the quality and length of my life?
- Do you have a palliative medicine team you routinely work with? (See page 18 for more information on palliative care.)

Palliative care does not try to cure a disease but seeks to soothe, prevent, relieve, or reduce symptoms. It may also include treatments to help patients reach personal goals, obtain meaning from everyday life and current experiences, and overcome conflicts associated with the end-of-life.

- When is the right time to get a palliative care team involved in my care?
- How will I know when my heart condition is worsening? What signs or symptoms should I expect?
- Is frequent hospitalization a sign that my heart failure has worsened to the point that I should think about end-of-life issues?

Also, be sure to write down any additional questions you may have about heart failure and your condition.

Questions to ask my Doctor or Nurse

Discussions with Your Doctor or Nurse

Your doctor or nurse will also want to learn about your concerns, goals, and values during the advance care planning process, so they can provide the care that is right for you. Some of the questions they may ask include:

- What is your understanding of heart failure?
- What does quality of life mean to you?
- What are your hopes?
- What, if anything, are your fears? What are you most afraid of?
- What would be left undone if you were to die today?
- Has faith been important to you at specific times of your life?
- What has provided the most meaning in your life?
- Can you imagine a time when it would not be worth it to stay alive?
- Which heart failure symptoms bother you the most?
- What practical problems is your heart failure creating for you?
- Do you have effective methods for treating your symptoms of heart failure?
- Is there a specific resource you use (person, place, thing) to help you feel better?
- If you have lost family members or other loved ones, what was that like for you?
- Are there family members who need to know what is going on?

To prepare for a discussion of advance care planning with your doctor or nurse, you may wish to write down the answers to these questions.

Making Care Choices as Heart Failure Progresses

Some people worry about burdening their families as their heart failure progresses and about dying in pain. When patients and families are told "nothing more can be done", they often interpret this to mean that their doctor or hospital will no longer care for them. This is not true. You are entitled to continue to receive medical care and have your pain managed no matter what stage of heart failure you have. Additionally, you can choose how you will be cared for and where you receive that care as your heart failure progresses. Some people prefer to be cared for and die in their homes. Others may prefer to die in a hospital.

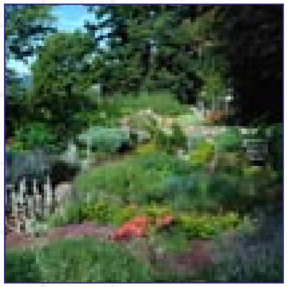
The following sections discuss some care options:

- Palliative care.
- Hospice care.
- Home health care.
- Other supportive care.

Palliative Care

Palliative care programs are designed to improve the quality of life of patients and their families when they are faced with a life-threatening illness. Since the course of heart failure may not be predictable, this type of program does not have the same entry requirements as a hospice program, which typically requires patients to have a life expectancy of 6 months or less.

Palliative care programs are very similar to hospice programs in that their goals are patient comfort and quality of life rather than cure. They typically take many dimensions of a person's life into account (physical, social, spiritual, and psychological) and seek to individualize care to meet the unique needs of each person. In addition, patient education is part of the care plan and can include education about ways to decrease shortness of breath, conserve energy for important activities, and monitor your condition.



Hospice Care

Hospice programs promote the notion that dying is a normal part of living. These programs provide medical and supportive services to a patient expected to be in the last 6 months of life. Hospice care can be provided in different settings including the patient's home, a hospice unit, or a nursing home.

Hospice programs are intended to provide care and support 24 hours a day, 7 days a week according to the following guidelines:

- The goal of care is to comfort rather than cure the patient.
- Pain relief and symptom control are designed to meet the needs and desires of the patient and are obtained by whatever means necessary.
- The patient is not treated in isolation. The family is included in the unit of care.
- The patient and family can control and set the agenda for day-to-day care.
- A multidisciplinary team that includes nurses, volunteers, chaplains, therapists, bereavement counselors, social workers, and doctors are there for the patient.
- Care includes a spiritual component (not specific to one religion or faith) to help patients discuss and reconcile the meaning of end-of-life.
- Long-term bereavement support is available for family and friends.

Making Care Choices

Home Health Care

Whether you choose a palliative care program, a hospice care program, or no program at all, it is likely that you will feel more tired and be short of breath as your heart failure progresses. Your doctors and nurses may recommend home health care nursing to monitor your status and adjust your therapy to keep you comfortable without shortness of breath.

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

Other Supportive Care

Occupational therapists, respiratory therapists, and physical therapists can help you move and breathe more easily and keep your muscles conditioned so you have fewer aches and pains with movement. These health care providers can also help you get equipment so you can do your day-to-day activities more easily. Examples include a shower stool, wheelchair, scooter, home oxygen, or a ramp that goes over the stairs.

What to Do with Your Advance Care Plan

Make copies of your living will, do-not-resuscitate order, health care power of attorney, or other directions about medical treatment decisions (even if they are hand written) and give them to your health care team. If you need to be treated in a hospital, bring a copy with you. The hospital or your doctor will keep a copy of these documents in your records so that they have access to your wishes should they be needed. If you have a health care power of attorney, give the person or persons you have designated a copy of these documents as well.

You may also wish to carry a card in your wallet which states that you have certain advance care directive documents and include contact information for the people who have copies of the documents.

Once you have prepared an advance care plan, be sure to review and update it every few years to make sure it still describes your wishes and meets current legal requirements.

Changing Your Mind

It is common for people to change their mind about their medical care. You can always change or cancel advance care documents, provided you are capable (competent). If your wishes change, be sure to let your family and health care team know, so that they can provide you with the type of supportive care that you really want.

Care for the Caretakers

Taking care of a family member or friend with heart failure can be a source of pride and a way to express love for that person. However, caretakers can also get tired and may need support. This is particularly true as the person with heart failure gets sicker and needs more help. Caretakers may ignore their own health, because they are so busy caring for their relative or friend with heart failure.

Asking for help from other family members and friends or from home health nurses and aides can help prevent caretakers from feeling overly burdened. Supporting caretakers as they help a family member or friend who has heart failure is an important part of helping families.

Terms Commonly Used in Advance Care Planning

As you work on an advance care plan, it may be helpful to familiarize yourself with the following terms.

Advance care directives: A document that lets a person give directions about his or her future medical care or to choose another person to make medical decisions if the person is not able to make decisions about his or her health.

Coma: A state of permanent unconscious deep sleep.

Do-not-resuscitate order: A type of advance directive that specifies when CPR, types of medical treatment, or technology are to be used or not used to revive a person if they stop breathing or if their heart beats irregularly or stops entirely.

End-stage heart failure: A stage of heart failure when there is a loss of response to maximal therapy with medicines and devices, and the patient has experienced repeated hospitalizations over the past three months due to severe, ongoing symptoms and distress, and a heart transplant or support with a ventricular assist device is not feasible.

Health care power of attorney: A document that involves choosing a person to be an attorney-in-fact regarding all health care decisions, including the decision to refuse life-sustaining treatment when the person is unable to make decisions themselves. A durable health care power of attorney remains in effect even after you become incapacitated.

If the person has a living will, the person holding the health care power of attorney has the authority to interpret the living will in the event of questions and make decisions that he or she believes to be in the best interest of the person.

Hospice: A type of care program that supports patients and their families through the dying process and helps surviving family members through bereavement.

Living will: A legal document that lets a person who is unable to make decisions (usually because of inability to communicate during a terminal illness) express their wishes about life-sustaining treatment.

Palliative care: A type of care program that can be used when a disease is no longer responsive to curative treatment. Palliative care generally involves treatments that seek to soothe, prevent, relieve or reduce symptoms.

Resuscitation: Taking measures to save a person's life in the event they stop breathing, their heart beats erratically, or their heart stops beating.

Sudden cardiac arrest: When the heart suddenly stops pumping enough blood to sustain life, because an electrical problem in the heart causes an extremely fast and/or chaotic heart rhythm.

Terminal illness: An illness in which death is expected to occur with or without medical intervention. The term also applies to an irreversible condition, when there is no reasonable chance for recovery.

Permanent vegetative state: A state that occurs when there has been permanent brain damage severe enough that the person is unaware of their surroundings. The person can not communicate, understand, or meaningfully appreciate life, and there is no reasonable chance for recovery.

The information in this module is merely a guide to advance care planning. It is not intended to replace professional medical advice, legal advice, or state laws as related to advance care planning.

Learn More

You can learn more about how to take control of your heart failure by reading the other modules in this series. You can get copies of these modules from your doctor or nurse. Or you can 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
- Tips for Family and Friends
- Lifestyle Changes: Managing Other Chronic Conditions
- 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.

Notes: