Living with
Advanced Congestive Heart Failure:

A Guide for Family Caregivers

By

The Washington Home Center for Palliative Care Studies
A Division of RAND Corporation
(formerly the Rand Center to Improve Care of the Dying)

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Living with Advanced Congestive Heart Failure: A Guide for Family Caregivers is a collaborative project based on the experience and knowledge of many health care professionals from around the country. This manual was made possible by funding from the AARP Andrus Foundation.

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In addition, much of the information in this manual is based on the work of a national quality improvement project aimed at improving care for people with advanced lung disease. Physicians, nurses, social workers and other health care professionals from 47 health care organizations hospitals, Veterans Affairs Medical Centers, hospices, home health agencies, and other facilities around the country participated. The RAND Center to Improve Care of the Dying, the Institute for Healthcare Improvement, and the US Department of Veterans Affairs sponsored the project. The project aimed to find ways to help lung disease patients and their loved ones manage illness while staying at home and avoiding unnecessary hospitalization. Thanks to their work, we are able to share proven advice, ideas, and strategies that enhance the quality of life for people with lung disease and their caregivers.

A team of public health and health care professionals wrote and edited this material:.

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NOTE: The following information is intended only as a supplement to medical advice. Please consult a physician for individual guidance and recommendations.

INTRODUCTION

More Americans will die from diseases of the heart and the circulatory system than from any other cause. For most, the death will seem sudden, even if the person has been ill for some time. People with advanced heart disease have episodes of serious illness, and then long periods in which nothing seems to happen. Although people may recover, they may not return to their previous level of functioning–and yet, at times, they may not seem to be very ill.

Congestive heart failure (CHF) is a progressive and eventually fatal illness. The nature of the disease makes it difficult to predict how much time a person has. Your loved one's physician is the best person to ask about prognosis. As the disease progresses, you and your family member should discuss changing treatment options and important end-of-life decisions with the medical team and with one another.

Advanced heart disease, like so many chronic illnesses, *afflicts* one individual, but *affects* entire families. Family caregivers are essential in helping the person with the disease–and families and friends become involved in making practical arrangements to care for the patient on a day-to-day basis. People with advanced CHF may need help with daily tasks, such as fixing food and getting dressed, and with other chores, such as running errands and housekeeping. At some point, the helpers or caregivers often become involved in providing health care support, such as managing medications and coordinating physician visits.

Although many family caregivers live with the patient, many others do not. Some family caregivers may live at a great distance, but still provide essential care. No matter where you are in your journey as a family caregiver, and no matter the degree of care you provide, this manual can help you and your loved one live more comfortably with advanced congestive heart failure.

Many organizations offer resources and information on preventing and treating heart disease; such materials usually focus on lifestyle changes, such as improving diet and quitting smoking. But no organization offers guidance specifically for family caregivers with a focus on coping with advanced heart failure. This manual focuses on five key topics for family caregivers:

1. Advanced heart disease and its progression
2. Disease management strategies to help patients remain comfortable and at home
3. The role of the family caregiver
4. End-of-life issues and how to make advance care plans
5. Living well with the disease

As you read, talk to your loved one and make sure that you both understand the information provided. You will need to talk openly and frequently with your loved one and you will want to confer with health care professionals. As you read, be sure to:

- Understand the material in each section. If something is unclear, can your family member explain it? If not, ask the doctor or nurse.
- Answer questions about yourself and your loved one. If possible, compare answers.
- Talk to your loved one about his wishes and preferences for care. Make sure that you both understand those decisions–and convey them in writing to the doctor or medical team.

PART I

CONGESTIVE HEART FAILURE: THE BASICS

By understanding some basics about congestive heart failure (CHF) and its symptoms, you will be better prepared to care for your loved one and talk to his or her physicians. This section provides general information about how the heart works–and how CHF affects the heart and other organs.

What is Congestive Heart Failure?

Having congestive heart failure means that the heart is not working as well as it should. It is losing its ability to pump blood effectively which has a negative effect on many bodily functions. Because a weakened heart moves less blood with each pump, fluid backs up in the lungs. As a result, the body does not receive enough oxygen. The kidneys cannot work properly in removing excess fluid from the body and fluid accumulates in parts of the body, particularly the feet and lower legs. The body becomes “congested” with fluid–hence the phrase, “congestive” heart failure.

What Causes CHF?

Usually there is an underlying condition or disease that weakens or damages the heart muscle and causes CHF. The most common cause is coronary artery disease which narrows the blood vessels that supply the heart, depriving the heart muscle of oxygen and weakening it. Other causes include:

- Residual damage after heart attack
- High blood pressure (hypertension)
- Damage to heart muscle from other causes, such as infections
- Severe lung disease
- Problems with heart valves

Other conditions can make heart failure more like to develop, such as:

- Obesity
- Diabetes
- Chronic kidney disease
- Abnormal or irregular heartbeat (ar

How Does CHF Progress?

Heart failure is a progressive, chronic disease. This means that that it is a long-term condition that worsens over time.

In the early stages of CHF, the heart tries to compensate by:

- **Enlarging:** The heart enlarges initially, just as it would to meet the demands of regular exercise. Over time the heart muscle stretches and weakens.
- **Increasing its muscle mass:** More heart muscle fibers enable the heart to pump more strongly.
- **Pumping faster:** To increase the output of blood flow from the heart into circulation.

Because the heart can compensate, people can live with heart failure for quite some time before it is diagnosed. Eventually, the heart cannot keep up, and a person loses energy, gets short of breath, or experiences other problems that lead to a doctor's visit.

How is Heart Failure Diagnosed?

Several tests can be done to determine whether or not a person has CHF. These tests determine whether the heart is working as well as it should be, and if it is not, where the problem lies. Common tests include chest x-rays, echocardiography, cardiac catheterization, stress and blood tests, and MUGA scans.

CHF is a **chronic illness** because it doesn't go away and generally worsens over time. Although the symptoms can be treated, the disease cannot be cured.

PART II

MANAGING HEART DISEASE AT HOME

There's no place like home….especially when you are sick. Most people with serious illness want to stay at home (no matter where that home is–it can be an assisted living facility or other long-term care environment). Family caregivers play an important role in helping patients recognize and treat symptoms to prevent a medical crisis and to avoid unwanted or unnecessary hospitalizations.

Following the strategies in this section does not guarantee that your loved one will avoid trips to the emergency room altogether. But it can help reduce the number of those trips, and will enable both of you to feel less anxious or worried about what is going on.

Although the information here is geared toward a family caregiver based at home with the patient, other caregivers will benefit from learning more about what is needed to care for the patient. It is especially important to understand the treatment, and to be aware of your loved one's treatment preferences.

What Do I Need to Care for My Loved One at Home?

Talk to your family member about what he would need to do to have a good day. Begin by reviewing the following information; together, talk to the doctor or nurse about keeping an adequate supply of prescription medications on hand. At a minimum, you and your loved one will need:

1. A scale to record daily weight, and a plan to treat any sudden weight gain (an indication of possible problems).
2. Routine medications and diet plan. Also, a "stand-by" set of medications to immediately treat pain, shortness of breath and weight gain.
3. A plan for whether or not to go to the hospital in an emergency and whether or not to try CPR.

By following the steps on the next few pages, you'll be able to help your loved one stay comfortable and stay home.

What Are the Basics of Disease Management?

Caregivers can support their loved ones by following a few basic steps. Many of these require you to talk to your loved one and to work out a plan. Whenever possible, write down your plan and keep it where both of you–and any back-up caregivers–can locate it. **Key steps are to:**

Step 1: Keep a daily log

By keeping track of basic information, you will be able to provide the doctor with accurate and up-to-date reports, either over the phone or during visits. This record does not need to be complicated. In fact, the simpler, the better. A spiral-bound notebook or composition book will do just fine. Have your loved one get in the habit of recording the following information each day:

- Breathing–easy, difficult, coughing, and so on
- Medications–names, doses, and times, as well as any side effects
- Diet and activities
- Other symptoms to discuss with your doctor, such as swelling

Step 2: Know When to Call the Doctor

The following symptoms merit a call to your loved one's doctor or nurse. Review this list with your loved one.

- A gain of 3 pounds or more within a few days or a week
- Increased swelling in hands, ankles or feet
- Difficulty breathing at any time or coughing at night
- Decreased urination
- Confusion, dizziness, or faintness
- Nausea or vomiting
- Increased fatigue
- Muscle cramps or weakness
- Any distressing symptom

BOTH of you should know when a call to the doctor is necessary.

Additionally, having specific "stand-by" medications on hand at home, and knowing exactly when and how to use them, can mean getting a head start on treating worsening symptoms. You may want to ask the physician whether this type of "emergency" treatment plan is appropriate for your loved one and how to set up one up.

QUICK TIPS

- **Keep paper and a pen by the phone to write down medical instructions.**
- **Tell the doctor or nurse about any medications your loved one is taking.**
- **Ask questions. If you don't understand what the doctor or nurse recommends, ask them to clarify.**

Step 3: Know Who to Call

Keep the following information handy–and be sure that everyone knows where it is:

Medical Contact:________________________________

Telephone Number: ______________________________

Pager/Afterhours: _______________________________

Alternate Contact (If first contact is unavailable):

Contact: ____

Telephone Number: ______________________________

Pager/Afterhours: ________________________________

Step 4: Be Prepared with Information the Doctor Will Want

Your conversation with the doctor will be more effective if you can give the following information. These are just some of the questions you may be asked. Knowing this information ***before*** calling the doctor or nurse will make your exchange more effective.

Be prepared to tell the doctor or nurse if you are concerned about…

✓ **Chest pain**
  - Location
  - Character (sharp, aching, shooting, etc.)
  - When did it begin? Is it constant or intermittent?

✓ **Weight gain**
  - What is the patient's normal weight?
  - About how many pounds has she gained?
  - Over how many days?

✓ **Swelling**
  - Where is the location of the swelling? (Hands, feet, ankles?)
  - How long has the swelling been present?

✓ **Difficulty breathing or coughing at night**
  - When did the breathing trouble begin?
  - What makes breathing more difficult? What makes it better?
  - When did the night coughing begin?

✓ **Decreased urination**
  - How many times has the patient urinated in the last 24 hours?
  - What is the urine's color and odor?

✓ **Feeling dizzy, faint, or confused**
  - How long has the patient felt this way?

✓ **Nausea or vomiting**
  - How long has the patient felt this way?

✓ **Increased fatigue**
  - How long has the patient felt so tired?

✓ **Muscle cramps or weakness:**
  - Which part of the body is cramping?
  - How long have the muscle cramps or weakness been going on?

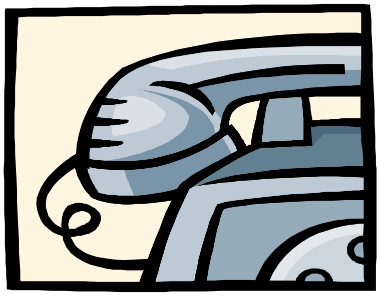
✓ **Any symptom that distresses you or the patient is worth a call to the doctor.**

Step 5: Have an Action Plan

1. Don’t Panic

Shortshortness of breath or other symptoms can be frightening. Keep calm, and try to calm your loved one. Remember, help is just a phone call away.

2. Call



Call the doctor or nurse.

Have the number handy and be prepared to answer questions about the symptoms your loved one is experiencing.

3. Follow Instructions

Often the doctor or nurse will give you instructions over the phone on things you can do to relieve symptoms.

This might be taking additional medications or making a trip to the hospital.

Be prepared to follow the instructions. If you don’t understand what you are told, ask the nurse or doctor to explain again.

PART III

THE CAREGIVER'S ROLE

Severe heart disease once killed people very quickly. New medications and better symptom management have improved prognosis, and many people now live for five or more years after diagnosis. Even so, CHF is an eventually fatal illness with an unpredictable course. Most people with serious heart disease have episodes of serious illness and then long periods in which nothing seems to change. However, over time, symptoms worsen. If the person with CHF avoids other serious illness, CHF itself will eventually cause death.

Most people with advanced CHF reach a point at which they need the help of a caregiver to accomplish tasks they can no longer manage alone. Family caregivers may be spouses, adult children or other relatives–or they may be good friends or long-time companions. In some cases, family caregivers live with the patient. Many caregivers, however, do not - and rely on friends, neighbors, and paid help to assist with care for their loved one. Regardless of the arrangement, family caregivers need to have information about the patient's illness, current treatment, and treatment preferences. If you are a primary caregiver, be sure to share this information with others who care for your loved one.

HELP FOR CAREGIVERS

- Start with the basics. Ask the doctors and nurses: What will my loved one need? How can I help?
- Consult a social worker or case manager, especially to understand Medicare and Medicaid rules and what facilities and services might be available.
- Use a support group. Even if a caregiver is a little uncertain about meeting with others, try it a few times. Most people find it enormously helpful to hear how others have met challenges and to share stories with others who have really "been there."
- Get information from the relevant national organizations. All kinds of good information is posted on the Internet, and a librarian can help you get it if you don't have access. Some groups also have toll-free phone numbers.
- Contact a local hospital or hospice to locate support groups and special services that they might have for people who face similar challenges.
- Do some research, either in the library, on the Internet, to get additional information. Try to become something of an expert on the particular illnesses affecting your loved ones.
- Call on family and friends–don't do it all alone.

Adapted from *Helping Yourself, Help Others*, by Rosalynn Carter with Susan K. Golant

Living with uncertainty is difficult. If you live with or care for a CHF patient, you can help manage the disease by paying attention to certain symptoms, following some basic guidelines, and staying in touch with the health care team. Caregivers can do many things to help their family members maintain a good quality of life. Caregivers also need to watch out for their own emotional and physical well-being.

How will I know if things are getting out of control? Caregivers can find it difficult to keep some perspective on what is happening. Although caregiving is often stressful, most caregivers find ways to manage–and do well. Caring for a loved one who is often short of breath and anxious can be taxing, overwhelming, and sometimes even scary. If you find yourself feeling more and more exhausted, depressed, angry, and unable to sleep or eat well, you should look for more help. If you feel that there is no one on whom to call for help, discuss your concerns with your loved one's doctor. Many caregivers experience periods of terrible isolation. This isolation can be a symptom that you are overwhelmed.

I feel overwhelmed but don't know what to do. Frequently caregivers do not maintain connections with the rest of the community. Often, re-connecting with friends helps. If you were active in a church or social organization or are close to neighbors, ask friends for help. Most people are happy to pitch in and offer encouragement, if they have been asked.

Isolation can really sap your self-esteem and your ability to reach out for help. If at all possible, join a support group and get together with people who are "in the same boat." Even if you have to hire a sitter for a few hours or bargain with a neighbor for help, try hard to get a break and get out in the world.

Where can I find a support group? Ask around. Try your doctor, nurse, and social worker. Try hospitals and nursing homes in the area. Call national organizations to ask how to contact a local chapter. (There are national resources listed at the back of this manual.) Check with your local Area Office on Aging, which usually has a list of helpful services that is available to the elderly; those services are often available to younger persons also. Call your church or other religious institution. Call other religious institutions that are geographically close even if they are not associated with your religious tradition. A support group at any church or synagogue is usually quite welcoming to persons of all faiths. Then, try it out a few times. If you don't find it supportive, move along and try something else. Some people are finding a great deal of support by joining in chat rooms or listservs on the Internet. If you do this, be careful: it is hard to know whether the information being given is honest or accurate.

REST AND RENEWAL TIPS FOR CAREGIVERS

- Hire a sitter or an aide for occasional events or on a regular basis.
- Arrange for other family members or friends to provide care.
- Use a nursing home or assisted living facility for planned vacations of a week or more.
- Use a day hospital or adult day care.
- Ask a family member or friend to take over some routine responsibility, such as helping with cooking or bathing.
- Change your expectations for yourself: let the housework go more than you like, for example.
- Meditate or pray.
- Recognize that for some people, nursing homes or assisted living facilities are the best option.

PART IV

PLANNING FOR THE FUTURE

Your loved one's condition will change over time as the disease runs its course. Along the way, be sure to talk to your loved one and to physicians about what changes in the disease mean in terms of treatment planning and options. Be prepared to discuss changes in plans–and know that decisions can always be revisited and revised.

Because CHF is a life-limiting disease, you and your loved one need to think about the future and make plans for what will happen as the disease progresses. It is essential that you talk about the kinds of treatment your loved one wants near the end of life–and the kinds of treatment he does not want. You might approach these discussions as *"what if?"* planning:

- ***What if*** you have pneumonia – what kind of treatment do you want?
- ***What if*** you are unable to breathe without the aid of a machine?
- ***What if*** you cannot talk or write or communicate your wishes?
- ***What if*** someone else needs to speak on your behalf?
- ***What if*** your doctors recommend removing machines?

Such *"what if?"* planning, though uncomfortable at first, will help both of you feel more in control. As a caregiver, you are probably hesitant to burden your loved one with *"What if?"* questions about the future. *"What if?"* issues can be very difficult to raise, especially when you're trying to be positive. However, you need to work together to plan for the future.

What Kinds of Decisions Will We Face?

You and your loved one will face important decisions–and it is best for everyone if these decisions can be made in advance, before a medical crisis. Each person's values and beliefs should guide medical choices whenever possible - not the other way around.

Such planning isn't the same as giving up. Actually, advance planning is a way for patients to control their own destinies and make things easier on family members. Though it's difficult, dealing with these issues ahead of time can bring peace of mind.

How Should We Ask About Prognosis?

When someone is diagnosed with a serious disease, including heart failure, our first instinct is to ask, "How much time does he have?" The doctor may not be able to answer this question, or at least, not very accurately. The doctor is not trying to evade the issue. But the nature of heart failure makes the timing of episodes of severe illness, and even dying, very unpredictable. Most people who die of heart failure were stable in their usual state of health just a few weeks earlier.

Both prognosis and treatment plans are likely to change over time. Despite the uncertainty with which you live, it is important to ask the doctor about your loved one's prognosis. This should not be a one-time conversation. Instead, you should revisit it from time to time as your loved one's condition changes, or when you have questions about treatment. These conversations are important during any treatment planning, especially when your loved one is becoming more disabled or sick because of CHF more often.

It is hard to talk about prognosis. You may be inclined to delay these conversations "for another visit." **Don't!** Talking about the future is easier if you address concerns at nearly every office visit. Here are a few questions to ask:

- What usually happens to people who have CHF–what kinds of complications do they face?
- How long do they usually live? What kinds of treatment do they need along the way?
- How do people with CHF die?
- What is the best we can hope for?
- What is the worst that we might have to face?
- What kinds of medical problems might come up? Can we plan ahead to manage them?
- How will this illness and its treatment affect my loved one? How will it affect our family?

When something new arises, ask: "Does this change what I can expect?"

Expect that many doctors won't really know the answers. Ask the doctor, "How many patients with heart disease have you followed to death?" If your doctor doesn't really have any experience, find someone (another doctor, a home health nurse, a hospice professional, or a support group leader) who has "been there" before.

Can We Refuse Treatment?

Caregivers and patients need to talk about which life-sustaining treatments are wanted–and which are not. Among the most difficult decisions are those surrounding treatments such as artificial nutrition (“tube feeding”), intravenous (IV) hydration, antibiotics, and ventilators (breathing machines). These treatments are usually put in place because there is some hope that a patient is going to recover from a temporary setback. Deciding to use these treatments in the course of a serious, chronic illness demands careful consideration. Once treatments have begun, it can be hard to decide to stop. You and your loved one need to know that treatment can be stopped whenever you decide to do so.

When making any medical decision, weigh the benefits and burdens. Artificial treatments that extend life are often very effective. Many people are alive today because of such treatments. Indeed, when there is any doubt about whether a treatment will improve comfort or quality of life, a “time-limited trial” is often very useful. The key is to define the time limit before starting the treatment, so that everyone realizes that it will be reassessed. The burdens of a treatment should not be ignored just because it has been started and is ongoing. If a treatment is not improving the patient’s life or prospects, it should be stopped.

What Do We Need to Decide About Ventilators?

Ventilators push air and oxygen into the lungs and often extend lives. Ask the doctor about situations in which a ventilator would be useful–and situations in which it should not be used. Be sure the doctor knows what your loved one wants–and will respect those choices.

PROBLEMS WITH VENTILATORS

Ventilators may interfere with the ability to communicate and swallow.

Ventilators do not cure disease. They keep the patient going.

Ventilators are uncomfortable.

Very sick people may or may not be able to recover enough to breathe without the ventilator.

Patients may require extra sedation while on the ventilator.

Many blood tests and X rays may be needed to monitor the patient’s condition.

As with other end-of-life decisions, this one is complex because of the emotional issues raised by stopping a ventilator. Remember that it is your loved one’s right to decide to forgo all use or to have a time-limited trial with a planned withdrawal if there is no improvement.

What Will We Need to Decide About Resuscitation?

If someone's heart stops, blood no longer circulates, and the person will die unless the heart is restarted immediately. Since a person's sudden collapse must be addressed so quickly, many people are trained to make the efforts needed to restart circulation right away by using cardiopulmonary resuscitation.

In the case of a seriously ill person, however, cardiopulmonary resuscitation (CPR) may not be what is wanted. It may not be successful. It is rarely effective in those who are very sick, and life after resuscitation can be short and usually involves use of a ventilator. You and your loved one need to discuss whether or not to attempt CPR.

If your loved one decides against trying resuscitation, how can you prevent people from trying anyway? Have a direct conversation with the doctor and with others involved in caring for your loved one to be sure that everyone understands what is wanted. If your loved one is in the hospital, his doctor can write a do-not-resuscitate order (DNR) to be added to the medical chart. Medical and emergency staff are not to attempt CPR on a person who has a DNR.

Nursing homes follow a similar process, although it may be entrusted to a primary nurse. Ask how your family can ensure that your loved one's wishes are followed. Be clear about whether your loved one should be sent to a hospital if he should become quite ill. If he is at the point that he would want to go to a hospital only to relieve symptoms, or not at all, be sure to make that wish clear.

If your loved one is at home, CPR may be less likely to occur, unless someone panics and calls 911. You can ensure that the emergency crew will follow your loved one's wishes, but you must find out what the process is in your state and follow it.

Deciding whether or not to have a DNR order sounds so simple. Yet this decision often causes much anxiety for families and health care providers. Why? Because these decisions are usually put off until the patient is too sick to be a part of the conversation. And making the decision means acknowledging that the patient might die. It really is easier to decide in advance and to take up the conversation during a normal day.

What is Advance Care Planning?

The decisions discussed in the previous section are all part of advance care planning. There are several kinds of **Advance Directives**, which are written instructions that a patient gives for future medical care, should they become unable to make decisions for himself (e.g., unconscious, too ill to communicate). There are two types of advance directive: a **Living Will** and a **Durable Health Care Power of Attorney**, or **Health Care Proxy**. Each patient has the right to change his mind and the responsibility to keep others informed of those wishes. Patients and caregivers should discuss these decisions–and any changes in them–and keep the health care team posted. Anyone involved in caring for your loved one should also be aware of his or her treatment preferences.

Someone with advanced congestive heart failure will want to cover the following points in detail:

- Naming a surrogate decision maker (a person who has the authority to make decisions if the person is too sick to make them)
- Stating what treatment results are desirable and which ones are unacceptable
- Talking about what to do in an emergency
- Stating preferences for time-limited trials (of artificial treatments such as ventilators, resuscitation, feeding tubes, etc.)
- Talking to physician and surrogate about preferences

Advance care planning is an ongoing process. As CHF progresses and circumstances change, your loved one may want to modify her preferences. If so, be sure to update all written instructions and share the changes with health care providers and anyone who assists with care.

What is a Living Will?

A Living Will explains a patient's wishes for medical care in case he or she becomes unable to communicate. State law may define when a living will goes into effect and may restrict the medical interventions to which it applies. One organization has developed a document called "Five Wishes," which is easier to read and complete than most other advance directives. Five Wishes complies with all legal requirements in more than 30 states. You can preview Five Wishes at http://www.state.fl.us/awd/order.html.

What is a Durable Health Care Power of Attorney or Health Care Proxy?

By naming a health care proxy, your loved one gives that person authority to make medical decisions on his behalf. The terms "health care proxy" and "health care agent" or "surrogate" are used interchangeably. These designations are considered "durable" because they remain in effect even if your loved one is unable to make decisions for himself. Most people appoint a close friend or family member. Some people turn to a minister or lawyer. The designated person should be able to support the patient's decisions, understand his treatment choices, and know what the patient values.

In some states, this person is allowed to make medical decisions for the patient only at the end of life, while in others he or she can make decisions at any time the patient is unable to do so. The doctor should be able to explain the law in your state.

This decision is extremely important. Your loved one's doctor should always know who to turn to for decisions when the patient cannot decide for himself.

Durable power of attorney forms do not give explicit guidance to the proxy about what decisions to make. Many states have developed forms that combine the intent of the durable power of attorney (to have an advocate) and the intent of the living will (to state choices for treatment at the end of life). These combination forms will probably be more effective than either of the two used individually.

How do we get started?

Each state regulates Advance Directives differently, so you'll need to consult with the physician, nurse, social worker or family lawyer to know what is required. While you're at it, take the time to make sure that financial matters, including wills and life insurance policies, are in order.

How will you know when the advance care plans are complete, that you've covered all the bases? A truly complete plan will:

- Be very specific and detailed and cover what is to be done in a variety of medical situations
- Name a health care proxy
- Be recorded in the medical record
- Be readily available to any caregiver in the home, nursing home, or hospital

Hospice

Hospice provides an array of services aimed at providing comfort care and support for individuals with a life limiting illness and their families. Hospice care is typically provided at home, but in-patient care is often also available. Hospice takes a team approach, using nurses, physicians, social workers, chaplains, nursing assistants, volunteers and other support staff to address physical, emotional, social, and spiritual needs unique to end of life care. One of the major benefits of hospice care is the support and guidance provided for family caregivers. You may want to ask the physician about the appropriateness of hospice care for your loved one.

PART V

LIVING WELL WITH HEART FAILURE

Heart failure cannot be cured, but it can be treated to relieve symptoms, such as fatigue, shortness of breath, and swelling. Treatment also can enhance a patient's energy level, ability to exercise and sense of well-being. In fact, many treatments can help prevent or slow the disease’s progression, enabling people with heart failure to live longer and more comfortably. Everyone's situation is different–treatments that work for one person may not be right for another. Patients and families need to talk to their physician about appropriate medical or surgical treatment options.

It is important to follow treatment recommendations–including recommendations about diet and lifestyle changes–no matter what stage of the disease you are facing. Failing to take medications, or deciding to disregard dietary guidelines, can worsen symptoms and can lead to a medical crisis.

LIFESTYLE CHANGES TO IMPROVE HEALTH

- Track medications taken–time, dosage, and side effects
- Watch diet–eat a balanced diet and limit salt intake
- Read food labels to determine salt content
- Try to maintain daily activity
- Quit smoking
- Get a yearly flu shot to avoid any illnesses that might complicate heart disease
- Avoid or limit alcohol consumption, it’s toxic to your heart muscle
- Talk to the doctor or pharmacist before taking cold medicines or other over the counter medications
- Keep an eye on emotional health and talk to the doctor if your loved one is depressed

MEDICATIONS

When determining which medications to prescribe, a health care provider will want to know about **all** of the medications currently being taken, including any over-the-counter medications, vitamins, home remedies, or natural supplements.

Once medications have been reviewed and any additional ones have been prescribed, it's important to take them exactly as prescribed. You can help your loved one to keep track of medications taken.

How can we keep track of these medications?

Complicated routines can be simplified by setting a schedule and following a routine. This checklist can help you and your loved one track the medication schedule. Write down the name of the drug, the amount to take and the time it should be taken. Make a checkmark (√) in the box to track dosage. Some older people have trouble following medication schedules. You might arrange to call your loved one and check that essential medicines have been taken.

Drug Name	**Dose**	**Time**	**M**	**T**	**W**	**T**	**F**	**S**	**S**

DIET

Following a well-balanced diet will help your loved one feel better and enhance his energy level. Like any healthy diet, a CHF diet should include plenty of fruits and vegetables, whole grains, and protein, such as chicken and fish. The patient should also limit the amount of salt in his diet.

Limit salt

Sodium makes the body retain fluid and makes the heart work harder, making breathing more difficult. One major source of sodium is salt. Reducing sodium intake will usually help lessen excess fluid and will improve the patient's well-being.

Ask your loved one's health care provider about specific recommendations on limiting sodium intake.

Read food labels!

Reading food labels is the best way to know how much salt is in the food you are eating. By reading the food labels you may discover that foods you thought were low in sodium (e.g., low in salt) really are not!

Control Sodium Intake By…

- **Checking the sodium content** of foods. Many frozen dinners, canned soups and condiments are high in sodium.
- **Removing the saltshaker** from the kitchen and dinner table. Out of sight, out of mind!
- **Using spices, herbs and other seasonings** instead of salt to flavor food. Garlic, oregano, basil, curry, onion, parsley, rosemary, and lemon juice are all good alternatives. Avoid spice mixes that taste salty. They generally contain other forms of salt that can be just as harmful. Check with the doctor before using salt substitutes which contain potassium. They can significantly change potassium levels, which can be beneficial or harmful, especially if your loved one takes prescribed potassium supplements.
- **Eating fresh and frozen vegetables** instead of canned vegetables. Canned vegetables can be very high in sodium because salt is used as a preservative. (Some frozen vegetables, such as those with cheese or cream sauces, can also be high in sodium.)
- **Eating fresh fish, poultry, and meat** instead of canned or processed meats.
- **Snacking on fresh vegetables** instead of salty snack foods, such as pretzels, popcorn or chips.
- **Avoiding salted crackers, muffins** and biscuits that contain salt, and stuffing mixes.

BEWARE: Other foods high in salt include sauces and gravies (especially those served in restaurants) and many fast food items such as french fries, fried chicken, and onion rings.

SMOKING

Stop Smoking

You've heard it a thousand times–and so has your loved one. Still, it bears repeating: Stop Smoking! And, if you smoke, don't smoke around your loved one. Some smokers think, "Why stop now?” But the truth is, it’s never too late to reap the benefits. Improvement in heart function starts within just a few weeks of stopping smoking.

Smoking is one of the most powerful irritants to the body and can quickly decrease lung function. This, in turn, will make symptoms even worse. Cutting down even on the amount of cigarettes smoked in a day will make a difference. Ask the physician or nurse about resources to help “kick the habit.”

EXERCISE

In general, it is best for people with heart failure to stay as active as possible. This may not seem logical–putting stress on a heart that is already having trouble pumping–but moderate exercise actually can help the heart get stronger.

Exercise has other benefits. It can improve symptoms, reduce stress, and increase energy levels. Additional health advantages to regular exercise include weight loss, better circulation and blood pressure, and lower cholesterol levels–all of which are especially important for people with heart failure.

Talk to your loved one’s health care provider about appropriate exercise. Physicians often use stress tests to evaluate how the heart functions during exercise (either walking on a treadmill or riding an exercise bike). This test can determine how much activity will be best for your family member.

PAY ATTENTION TO EMOTIONAL HEALTH

People with serious, progressive illness may feel very sad and down. However, these periods usually come and go. Sustained periods of feeling blue can actually be a sign of depression–which is a treatable illness.

One direct way to find out if your loved one is depressed is just to ask. Just asking people “are you depressed?” is a very good predictor of mental health. If she is depressed, recommend bringing it up with the doctor. Do not just ignore depression. With medication and therapy, clinical depression can be treated.

Common symptoms of depression are:

- Changes in appetite
- Changes in sleep–either sleeplessness or waking too early
- Feelings of guilt, hopelessness, and despair
- Fatigue
- Withdrawal from others
- Lack of pleasure in once pleasurable activities
- Thoughts of death and suicide

Family caregivers are subject to exhaustion and stress, and may also feel depressed. Be sure to ask for help from other family members and friends. If you are not able to cope, and if you are depressed, talk to your own doctor about ways to help yourself feel better.

GRIEF

Grief is a country we all must visit, and it helps to know what it's like there, how others have made the journey, the maps they followed, the setbacks, and what they learned along the way. Grief occurs many times in the course of an illness, both before and after the death of someone you love. Here are a few suggestions on how to live through grief, ways to grieve with and for the dying person, and how to cope during difficult times, such as holidays, birthdays, and other anniversary dates.

In taking care of a dying loved one, you may experience grief at many points throughout the illness. For instance, there is the grief of first learning about the person's illness, the grief as plans you shared are lost, or as you realize you may be spending your final days together. Throughout the course of a life-ending illness, you will encounter many milestones, and with each, experience some degree of loss. With loss, in general, comes grief and sadness.

A few notes about what has helped others:

- **Solitude helps.** You may need time to think about your loved one, to remember times you shared, to consider how your life will be now. You may be overwhelmed by your sorrow. You may want to stay in bed and cry or sleep, go for a walk, or sit in a chapel.
- **Other people help**. Friends and family members are likely to empathize with you. Even if they do not know what to say, just being with other people and talking can be supportive. Accept others' invitations to participate in activities - but leave if you feel you need to. Reach out to family or friends when the next hour or day seems unbearable.
- **Accepting support helps.** Others may want to help by doing things for you. They may want to bring you food or talk on the phone or run errands. Accept these acts of kindness whenever you can.
- **Rest and sleep help.** Caring for a dying person is exhausting. You may need time alone simply to regain your physical energy, as well as your emotional and spiritual strength.
- **Routines help**. Even though your life may feel turned upside down, try to keep up a routine of healthy eating, occasional physical activity (even a 10-minute walk), and regular sleep.
- **Time helps**. Your life may never be the same again. Whatever your experience with death and dying, you will find that you see the world and your place in it differently. Time lessens some of grief's pain, but it does not diminish your loss or sadness.

RESOURCES

BOOKS

Handbook for Mortals: Guidance for People Facing Serious Illness
By Joanne Lynn and Joan Harrold
Oxford University Press, 1999
258 pages, $28 Hardcover or $14 paperback

The Complete Bedside Companion: No-Nonsense Advice on Caring for the Seriously Ill
By Rodger McFarlane and Philip Bashe
Simon & Shuster, 1998
544 pages, $27

In the Country of Illness: Comfort and Advice for the Journey
By Robert Lipsyte
Alfred E. Knopf, 1998
252 pages, $24

The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers
By Maria M. Meyer and Paula Derr
CareTrust Publications, Inc., 1998
364 pages, $23

Living With Life-Threatening Illness: A Guide for Patients, Their Families, and Caregivers
By Kenneth J. Doka
Jossey-Bass, 1998
294 pages, $28.00

A Good Death: Challenges, Choices and Care Options
By Charles Meyer
Twenty- third Publications, 1998
64 pages, $6.95

Let the Choice Be Mine: A Personal Guide to Planning Your Own Funeral
By Cathy Robertson
28 pages, $6.00

The Good Death
By Marilyn Webb
Bantam, 1997
479 pages, $27.00 Paperback

Dying Well: Peace and Possibilities at the End of Life
By Ira Byock
Riverhead Books, 1998
299 pages, $27.95 Paperback

WEBSITES

Voluntary organizations with information on heart disease, end-of-life care, and family caregiving.

AARP
Information about long-term care financing, home care, and housing options. Look for the AARP Meeting Place, a support group for caregivers.
http://www.aarp.org/

Adult Care
Provides information on issues of importance to elders and caregivers through an e-mail question/response system called "Caremail"; it also provides current articles, books, and web links to other informative sites.
http://www.adultcare.com/

Aging with Dignity
Five Wishes®. An advance care planning document that is legally valid in 35 states.
Five Wishes Video. This 25 minute video highlights the importance of advance care planning, gives instruction on completing Five Wishes, tells what to do after you complete Five Wishes so that your wishes are followed, and answers common questions.
Information on ordering can be obtained by calling Aging with Dignity at (888) 5-WISHES.
http://www.agingwithdignity.org

American Heart Association
Detailed information on congestive heart failure, including diagnosis and state-of-the-art treatments.
www.americanheart.og

American Hospice Foundation
Information on hospice care, grief, and loss.
http://www.americanhospice.org/index.htm

Americans for Better Care of the Dying
ABCD aims to improve end-of-life care for all people, regardless of diagnosis or prognosis.
Download patient and family caregiver information from website.
http://www.abcd-caring.org

Caregiver.com
Contains back issues of Today's Caregiver Magazine, information on "Sharing Wisdom Caregivers Conferences", and a discussion forum.
http://www.caregiver.com

Caregiver Resource Directory
Offered by Beth Israel Medical Center, this practical guide is intended to help family caregivers feel less alone and overwhelmed. It offers resources, facts, and advice about caring for a loved one, as well as the caregiver. The Directory is designed as an interactive three-ring binder with

pockets and ample writing space so that caregivers can organize all resource and medical information in one place. The Directory can be ordered online at:
http://stoppain.org/caregivers/resource_form.html

Caregiver Survival Resources
One of the most visited caregiver sites, with links to resources, such as government and nonprofit agencies, and lists of local and regional resources.
http://www.caregiver911.com/

CareGuide
Resources for family caregivers. It includes everything they need to assess, plan, manage and monitor the best care for their loved ones.
http://www.careguide.com

Death and Dying
This site contains a wide variety of information about death and dying. The site has information about advance directives, caregiving, grieving, funerals, hospice and hosts chats open to the public.
http://dying.about.com/health/dying/

Family Caregiver Alliance
More than 20 years of advocacy and support for family caregivers. This site features online support for family caregivers, as well as bilingual information for Spanish-speaking people.
http://www.caregiver.org/

FAMSA – Funeral Consumers Alliance
Before I Go, You Should Know. An End-of-life planning kit containing state-specific Living Will and other advance directives, a place to record ones funeral and final preferences, plus a booklet that encourages family communication.
For Your Personal Information. A page offering a variety of information regarding affordable funerals and what people can do to plan them before their death
http://www.funerals.org/bookstor.htm

FRIA (Friends and Relatives of Institutionalized Aged) (New York)
Comprehensive Care Planning, What Families Need to Know and Do: Nursing Home Placements when there are Culture and Language Concerns (also available in Spanish, Chinese, Russian, and Korean), *Nursing Home Residents Bill of Rights* (*NY specific), *Problem Solving Techniques: Advocating for your Relative* (also available in Spanish).
http://www.fria.org/

Friends' Health Connection
Links caregivers of people with disabilities and chronic illness. It also has links to caregiver support organizations.
http://www.48friend.com

Funeral Consumers Alliance (FCA)
Before I Go, You Should Know. An end-of-life planning kit containing state-specific living will and other advance directives, a place to record ones funeral and final preferences, plus a booklet that encourages family communication.
For Your Personal Information. A page offering a variety of information regarding affordable funerals and what people can do to plan them before dying.
http://www.funerals.org/bookstore/index.htm

Gundersen Lutheran Medical Foundation
Making Choices: Planning in Advance for Future Healthcare Choices, Making Choices: Planning Guide, Making Choices: Video. Information on ordering these publications can be obtained by calling:
(800) 362-9567, ext. 6748, weekdays between 8:00am and 4:30pm CST
http://www.gundluth.org/

Heart Failure Online
Information and online support groups.
www.heartfailure.org

Heart Failure Society of America
Organized by cardiology experts, site includes information for clinicians and patients.
www.abouthfsa.org

Hospice Foundation of America (HFA)
In conjunction with the annual Living with Grief teleconference, HFA publishes the Living With Grief book series. Experts in grief and loss, educators, caregivers and clergy contribute chapters each year.
Choosing Hospice. This brochure details the basics of hospice, including services and payment.
Hospice Volunteers. This brochure discusses hospice volunteers, what they do and how people can become involved.
Hospice Care & The Military Family. This brochure provides an overview of the TRICARE hospice benefit.
A Guide to Recalling and Telling Your Life Story. A complete workbook designed to prepare and stimulate you to recall and tell your life story by suggesting topics and questions for you to consider.
http://www.hospicefoundation.org/index.shtml.

Last Acts
Loss and Grieving Series (Family Committee). A series of five brochures designed to provide helpful tips to specific audiences dealing with the grief process. The audiences addressed are children, friends, caregivers, healthcare providers, and the elderly.
Vision for Better Care at the End-of-life (Pallliative Care and Family Committees). This is a one-page flyer that describes the five principles upon which palliative car is based.
http://www.lastacts.org/section/resources/

MetLife
Offers children of aging parents a list of helpful books and in-depth information on several caregiving issues. Services require registration and verification of address.
http://www.metlife.com/Lifeadvice/Gateway/index.html

Midwest Bioethics Center
Caring Conversations. Downloadable from their web site and also available in hard copy, this workbook includes a process to help facilitate conversations about advance care planning, and advance directives.
http://www.midbio.org/mbc-ccorder.htm

National Alliance for Caregiving
Support for family caregivers and the professionals who help them.
http://www.caregiving.org

National Family Caregivers Alliance
Family Caregiver Alliance, is a support organization for caregivers. You will find specialized information on Alzheimer's disease, stroke, traumatic brain injury, Parkinson's disease, ALS and other disorders and long-term care concerns.
http://www.caregiver.org/

National Family Caregivers Association
NFCA is a grass roots organization created to educate, support, empower and advocate for the millions of Americans who care for chronically ill, aged or disabled loved ones. Some of their publications are: *Ten Tips for Family Caregivers, Caregiver Self-Advocacy Four Messages to Live By, A Guide to Improving Doctor/Caregiver Communication*.
http://www.nfcacares.org/

National Heart, Lung, and Blood Institute
Part of the U.S. National Institutes of Health, premiere research organization.
http://www.nhlbi.nih.gov

National Hospice Foundation
Hospice Care. A Consumer’s Guide to Selecting a Hospice Program. This brochure contains information on what hospice care is, what services are provided, and what key questions to ask when selecting a hospice program.
Hospice Care and the Medicare Hospice Benefit. This brochure helps patients and family members understand more about hospice care, as well as to learn what are the eligibility requirements for and what services are provided under the Medicare Hospice Benefit.
http://www.hospiceinfo.org

National Hospice & Palliative Care Organization
About DNR Orders. This booklet introduces Do-Not-Resuscitate orders and cardiopulmonary resuscitation (CPR).
Advance Medical Directives. This booklet introduces advance directives and advanced care planning.
About Dying. This booklet discusses death and typical responses to a loved one’s death.
http://www.nhpco.org

Partnership for Caring
Advance Directives, *Talking About Your Choices, Questions and Answers, Whose Death Is It, Anyway?* All are available on their Web Site.
http://www.partnershipforcaring.org

Rosalynn Carter Institute for Human Development
Georgia Southwestern State University has now established the National Quality Caregiving Coalition with the goal of establishing periodic meeting of professional and family caregivers, bringing attention to caregiving, and providing information to caregivers.
http://www.rci.gsw.edu/

Sacramento Healthcare Decisions
Finding Your Way: A Guide for End-of life Medical Decisions. This booklet guides individuals and their families through many end-of-life medical decisions. Information on ordering this publication can be obtained by calling:
(916) 484-2485, or by email at shd@quicknet.com

University of New Mexico: Health Science Center Ethics Program
Values History. Available in hard copy and on the web, this packet offers the opportunity for you to discuss your values, wishes, and preferences in a number of different areas such as your personal relationships, your overall attitude toward life, and your thoughts about illness.
http://www.unm.edu/~hsethics/valueshist.htm

Well Spouse Foundation
Offers spousal caregivers support in the form of local groups or e-mail “round robins.” The site also lists regional activities and publications for spousal caregivers.
http://www.wellspouse.org/

ADDITIONAL LINKS

American Association of Homes and Services for the Aging
http://www.aahsa.com

American Health Care Association
http://wwwlongtermcareliving.com

Andrus Foundation
http://www.andrus.org

Health Insurance Information, Counseling and Assistance
http://hiicap.state.ny.us/

National Institute on Community Based Long Term Care
http://www.ncoa.org/nicle/nicle.htm

Visiting Nurse Associations of America
http://www.vnaa.org/Home.htm