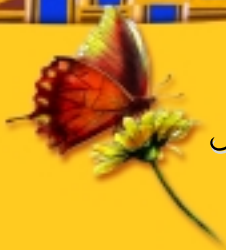


The Last Miles Home: Conversations before a crisis.



*A guide
for a **Better Ending***

Information on Advance Care Planning and Documentation from **Better Ending**,
a Program of the Central Massachusetts Partnership to Improve Care at the End of Life.

We don't like to think about it,

but at any moment we could face a serious medical crisis. One that could leave us unable to communicate with our loved ones or health care providers. Yet few of us have prepared for this.

The Central Massachusetts Partnership to Improve Care at the End of Life

was formed to help us prepare for this possibility and to improve the care that we receive when we are seriously ill or near the end of life.

The vision of the Partnership is that "All persons in Central Massachusetts live their last days in this life as comfortably as possible, in the setting of their choice, according to their expressed wishes, while they and their families are supported by a caring community."



IN THE TWINKLING OF AN EYE, IT CAN HAPPEN

Imagine that without warning, you have a life-threatening illness. You are unable to communicate with your loved ones, and you are not expected to recover. Imagine that you have survived a serious accident, but despite excellent medical treatment, you can no longer make decisions about your care. Or perhaps you have suffered through chronic illness that has progressed, so that you are no longer able to interact with others.

What if you are unable to communicate your wishes? What if you haven't told a loved one what is important to you? Do you want pain relief? Even if it means you would not be alert? Do you want a member of the clergy at your bedside in your final moments? What if your loved ones have different ideas and values? Your choices about care at the end of life may be very different from the choices of others, different even from members of your own family.

To ensure your wishes are followed you need to spend some thoughtful time, before a medical emergency occurs, discussing your values, your beliefs, and your choices for medical treatment if you become seriously ill. This brochure will help you to think through these important issues and guide you through the decision process. It will also help you communicate your decisions to your loved ones and your health care providers by:

THINKING AND TALKING IT OVER

Page 2 helps you to think about what you would want if you were seriously ill and unable to decide for yourself. You can choose someone you trust to make important medical decisions for you if you are unable to do so.

UNDERSTANDING WHAT YOU SHOULD EXPECT

Page 3 outlines the kind of care you and your loved ones have the right to expect if you have a serious or life-threatening illness.

LEARNING HOW TO MAKE YOUR WISHES KNOWN

Pages 4 and 5 guide you in writing down your wishes regarding your care. It also tells you about the File of Life and the Comfort Care or out of hospital Do Not Resuscitate (DNR) Form. A checklist for action is also included.

COMPLETING YOUR PERSONAL WISHES STATEMENT

You have the right and the opportunity while you are still able to let someone know what you want done if you become seriously ill. You should write down your wishes on the **Personal Wishes Statement**.

COMPLETING YOUR HEALTH CARE PROXY

The **Health Care Proxy Form** is the legal document in Massachusetts that allows you, if you are 18 years or older, to appoint, in advance, a person you trust to make medical decisions for you if you are unable to do so yourself.

Most people's lives
do not end suddenly.
Why not take the time
now to communicate
your wishes to those
who can help you live
your last days with
dignity in the manner
you desire?

Thinking It Over

Before you talk with those who care about you and those who care for you, you first need to think about what you would want if your life changed due to illness or injury. Here are some questions you may want to consider:

- ◆ What fears or worries do you have about illness or medical care?
- ◆ Do you have fears about a particular treatment?
- ◆ Who would you want to make medical decisions for you if you could not do so yourself?
- ◆ Do you have any religious or spiritual beliefs that would affect decisions about your care?
- ◆ Would you want your life prolonged, no matter what, if you were unable to interact with those you love?

Your Personal Wishes Statement presents some specific medical situations for you to consider if you are very seriously ill and nearing the end of life.

Your Loved Ones

After you have given thought to these questions, it's important to share them with your loved ones. Life experiences or a news story or a movie may provide an opportunity to begin these conversations. It may take several conversations to fully express your wishes. The important thing is to start the conversation. If the need arises, this ensures your wishes will be honored. This is an important gift you can give to those you care about.

Your Spiritual Support

African Americans are diverse in religious beliefs and exercise personal choice regarding religious practices. For many, Christianity and the church may provide comfort through its various denominations. Persons who are in the last miles of the way home and celebrating

life's blessings may expect or seek spiritual support from their church, pastor or others in their religious community. Muslims may rely on the mosque or imam to offer comfort and spiritual support. The acknowledgement of God can be central in the African American community and a great source of comfort. Some persons may not hold any religious beliefs or have organized faith traditions and may seek comfort from friends or family. Additional forms of spirituality not mentioned may also provide support.

Your Health Care Agent

While many people ask a spouse or other family member to be their health care agent, others choose a trusted friend. Here are some questions you may want to ask the person you are considering to speak on your behalf:

Will you, to the best of your ability:

- ◆ Respect my wants and needs, even if they are different from your own?
- ◆ Ask questions about my disease and what to expect as I get sicker and near the end of life?
- ◆ Make sure what I have asked for is done?
- ◆ Stay with me even if it gets difficult?

It's important to know that your health care agent can speak for you only if you can not speak for yourself, as determined in writing by your doctor.

Your Health Care Provider

Your health care provider plays an important role in making sure your wishes are honored when you become seriously ill. It is helpful to discuss these issues before you are in the midst of a medical crisis, so both you and your provider are satisfied with the support you may need.

The following questions may help to start the conversation with your health care provider:

- ◆ Will you explain the burdens and benefits of any treatment I might need?

- ◆ Will you promise to keep me as comfortable as possible? Would you consult with a comfort-care specialist if you have difficulty managing distressing symptoms?
- ◆ Would it be possible to stay at home and receive treatment?
- ◆ Would you be willing to continue my care if I wanted to have hospice?
- ◆ How much experience have you had caring for people who lived and died with this disease?
- ◆ What symptoms am I likely to have?
- ◆ Will you let me and my loved ones know what to expect as my illness worsens?
- ◆ Will you treat me as a person, not a disease?

WHAT YOU SHOULD EXPECT FROM YOUR HEALTH CARE PROVIDER

Despite the ability of modern medicine to treat and even cure many illnesses, we must remember there are limits to what technology can do. We may not be able to truly appreciate this until we become seriously ill. When this happens, what kind of health care should we expect?

First, we should expect that our wishes will be honored!

Also, Federal and state laws* ensure that in Massachusetts you have the right to:

- ◆ Considerate and respectful care
- ◆ Information about your condition and treatment
- ◆ Participate in decisions about your care
- ◆ Privacy and confidentiality
- ◆ A Health Care Proxy

Additionally, in 1999 major medical organizations adopted the following “core principles” to guide treatment for patients living their last days. Here are some excerpts:**

- ◆ Respect the dignity of both patients and caregivers.
- ◆ Be sensitive to and respectful of the patient’s and family’s wishes.

- ◆ Use the most appropriate measures that are consistent with patient choices.
- ◆ Reduce pain and other physical symptoms.
- ◆ Assess and manage psychological, social and spiritual/religious issues or needs.
- ◆ Offer continuity (the patient should be able to continue to be cared for, if desired, by his/her primary care and specialist providers).
- ◆ Provide access to any therapy that may realistically be expected to improve the patient’s quality of life, including alternative or nontraditional treatments.
- ◆ Provide access to palliative care (comfort care) and hospice care.***
- ◆ Respect the right to refuse treatment.
- ◆ Respect, with consideration for both patient and family preferences, the physician’s professional responsibility to discontinue some treatments when appropriate.

Now, before you are in the midst of a medical crisis, is the time to become familiar with these issues.

* MGL, Chap. 111, Sec. 70E

** from the Millbank Memorial Fund’s “Principles for Care of Patients at the End of Life: An Emerging Consensus Among the Specialties of Medicine,” by Dr. Christine Cassel and Dr. Kathleen Foley.

***Hospice is comfort care provided to patients and their loved ones so that their final months are lived as comfortably as possible, usually in their own home. All commercial insurance providers in Massachusetts are required to make hospice care available, and many hospices also provide care for those without health insurance. There may be some costs associated with services depending on insurance coverage. Contact your local hospice for more information.

A SIMPLE CHECKLIST

Use this simple checklist* to ensure you follow the steps to create a comprehensive advance care plan.

- I have thought about what is important to me and shared that with my family.
- I have chosen my Agent and Alternate.
- I have discussed my wishes with my (include date):
 - Agent _____
 - Doctors _____
 - Alternate _____
 - Spiritual Advisor _____
 - Family _____
 - Attorney _____
- I have completed my Massachusetts Health Care Proxy Form.
- I have completed my Statement of Personal Wishes.
- I have given copies of both my Health Care Proxy and Personal Wishes Statement to my:
 - Agent _____
 - Doctors _____
 - Alternate _____
 - Spiritual Advisor _____
 - Family _____
 - Attorney _____
- I have reviewed and updated my forms as needed.

Fill in the blanks identifying yourself, your health care agent and your alternate. It is not necessary to name an alternate, but it is advisable to do so if your health care agent is not available to act for you at all times. Sign the form in the indicated place in the presence of two adult witnesses. The witnesses must also sign the form, thus affirming they witnessed it and they believe you to be at least 18 years old, of sound mind, and acting of your own free will. Anyone age 18 or older, including a family member, can be a witness. Only your health care agent and your alternate may not serve as witnesses.

If you are physically unable to sign the health care proxy form, someone other than a witness may sign your name, provided he or she does so at your direction and in the presence of the two witnesses.

In Massachusetts, you do not need a lawyer to complete this form.

Your health care proxy becomes effective as soon as it is signed and witnessed. Your health care agent, however, cannot act for you until your physician has certified in writing that you are “unable to make or communicate your own health care decisions.” If your physician determines that you have regained the ability to make your own health care decisions, your health care agent’s authority to make them for you will cease.

You can make your specific wishes known to your health care agent in a conversation or in a separate personal wishes statement. You will not be able to consider every possible situation that might require your agent to act on your behalf, but you should let your agent know how you feel about those conditions, illnesses and treatments that concern you the most. If you wish to limit your agent’s authority in any way, you should describe those limitations

ADDITIONAL CONSIDERATIONS

specifically in the blank space provided on the health care proxy form.

Although not required, it is advisable to have your health care agent and alternate also sign your health care proxy in the space provided.

If you change your mind about your health care proxy, you can revoke it by tearing it up; by telling your health care agent, your alternate, your doctor, your nurse or your lawyer that you are revoking it; or by doing anything that clearly shows you no longer intend the health care proxy to have effect.

Your health care proxy will automatically be revoked if you fill out a new health care proxy form, or if you legally separate from or divorce a spouse who was named as your health care agent. Unless you revoke your health care proxy or it is revoked automatically, it will remain in effect until you die. Review it regularly to make sure the names, addresses and telephone numbers of your health care agent and alternate are current, and that your health care agent and alternate are still willing to serve.

Be sure to tell your doctor you have completed a health care proxy, and also make him or her aware of your treatment preferences; if you should go to a hospital, take a copy with you if possible.

Give a copy of your health care proxy to your health care agent, your alternate and your doctor. You may also wish to give copies to family members, your lawyer and your clergy.

Keep your original health care proxy with other important papers in a place that is safe but easy to find. Do not keep it in a safe deposit box.

(Please note that these instructions and forms are based on Massachusetts laws. Health care proxy laws and protocols, as well as the legal status of personal wishes statements, vary from state to state.)

Two programs complement the Advance Care Planning program.



The File of Life

Worcester and several towns in Massachusetts are implementing the File of Life program. It is used by many communities all over the country to provide Emergency Medical Service personnel or other First Responders information needed for emergencies. The File of Life is a 4" x 5" red folder with a magnetized strip that can be posted on your refrigerator. In the folder is a form to be filled out listing Emergency Contacts and providing essential medical information.

For additional information in Central Massachusetts, call Emergency Medical Services at 508-856-8171, ext. 2.

Comfort Care

The Commonwealth of Massachusetts has established a procedure for people living at home whose condition is such they do not wish to be resuscitated. If your heart stops, emergency medical personnel and other first responders must attempt resuscitation unless there is a valid Comfort Care/Do Not Resuscitate (DNR) Order present. The forms are available from and must be signed by your doctor. The Comfort Care order may be inserted in the File of Life folder. An identifying bracelet may also be used. The original form (not a copy) or the bracelet must be present for your wishes to be honored.

For more information, contact the Massachusetts Office of Emergency Medical Services at 617-753-7300, or www.state.ma.us/dph/oems/comfort/ccare.htm. Your doctor may also call the Department of Public Health Emergency Medical Services Coordinator at 617-624-6000.



The Central Massachusetts Partnership to Improve Care at the End of Life is a community coalition of professional, civic, business and religious leaders committed to a three-year program to achieve its vision. Goals include systemic improvements in the treatment of patients in the health care system, attention to the non-medical needs of patients and their families, and interest and support from key segments of the community: faith groups, estate attorneys, social service agencies, funeral directors, employers, and unions.

*Because achieving the vision and goals requires that a high proportion of the adult population have made their final wishes known, all of these community segments are promoting advance care planning as suggested in this **Guide for a Better Ending**.*

In November 2003, the Partnership received the national Award of Excellence for the best emerging end-of-life coalition from the Robert Wood Johnson Foundation's Rallying Points program.

**Central Massachusetts Partnership
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The Central Massachusetts Partnership is supported through the generosity of our many grantors and in-kind donors. Please call for further information, or visit our website for a list of supporters and how you can participate.

The Partnership is affiliated with the Massachusetts Compassionate Care Coalition.

If you would like more information about hospice services available in your area, please call the Hospice and Palliative Care Federation of Massachusetts at 781-255-7077.