

UniCare Advance Care Planning Initiative

‘Conversations before the Crisis – A Guide for A Better Ending’

October 2005

- Massachusetts Compassionate Care Coalition (MCCC) www.massccc.org
- Central Mass Partnership to Improve Care at the End of Life (CMP) www.betterending.org

UniCare

Thinking and talking about your death is hard, but planning for it can help you to live – and die - the way you want.'

www.unicare.org

UniCare Advance Care Planning Initiative

A major campaign to:

- Increase knowledge of the benefits of advance care planning
- Promote earlier meaningful conversations with loved ones and providers about your values and preferences
- Increase documentation of wishes among Plan members

Massachusetts Compassionate Care Coalition

- **Our Mission**

- To promote informed choice, dignity, comfort and compassionate care at the end of life through community-based initiatives

- **Our Vision**

- A culture in which the physical, emotional, social and spiritual needs of all seriously ill people are addressed through advocacy, education, committed care and community support.

Central Mass Partnership

VISION:

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.

'A Guide for A Better Ending'

A Guide for a Better Ending is one of many initiatives of the Central MA Partnership to Improve Care at the End of Life.

Goal: to improve advance health care planning for individuals and their families in the event of a serious or life threatening illness

www.betterending.org

Federal and State Laws

- 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
 - Refuse unwanted care
 - A Health Care Proxy

'A Guide for a Better Ending – Conversations before the Crisis'

What is Advance Care Planning?

- An ongoing process of exploring care options and values over time and of communicating those options and values to the proxy, to your loved ones and to your physician(s)
- Individualized process based on the culture, values and preferences of the individual and their family

What is a Health Care Proxy (HCP)?

-an advance directive in which an adult (over 18 years old) appoints (and educates) another person to make health care decisions in the event of incapacity
 - Mass. HCP is the legally binding document in Mass.
 - Requires 2 witnesses
 - No lawyer or notary required
 - Names a 3rd person decision-maker (and alternate, if desired)

What is a Personal Wishes Statement?

- Like a Living Will, it is not legally binding in Massachusetts
- However, it can be used to help guide your conversations and your values clarification
- It may be considered evidence of your wishes
- It should always be accompanied by a Health Care Proxy

'A Guide for a Better Ending' brochure

Why Is It Important – Why Now!?

- Aging demographics
- People are living longer with multiple chronic illnesses
- With longevity, comes responsibility and....
- Complex medical choices and decisions to make
.....or have made for us

What If I Do Nothing?

- People are still dying in places they don't choose
 - in ways they don't want
 - receiving treatments they wouldn't want
 - surrounded by strangers
 - in pain
 - their wishes unknown, undocumented, and often, not honored

Don't Leave It to Chance

- Ask yourself these questions –
 - Who would you want to make decisions for you if you couldn't?
 - What would be the goals of treatment if you permanently lost the ability to meaningfully know who you are, who you're with, and where you are?
 - Do you have important or unusual personal, religious, or cultural views that might affect your care?

Ask Yourself

- If you can't speak for yourself and can not come back to a meaningful cognitive state:
 - Would you want life-sustaining treatments such as:
 - Ventilator
 - Feeding tube
 - CPR (Cardiopulmonary Resuscitation)
- Would you want your life prolonged if you could not interact with those you love?

How to Choose an Agent

- Appoint someone you know and trust to speak for you
- Appoint a person who understands your values and beliefs – someone who will act as your advocate and honor your wishes and spoken preferences
- Choose a person who is comfortable discussing your wishes
- It does not have to be your spouse or blood relative – it may be a close relative or friend
- Be sure to talk with all those who will be at your bedside - including your doctor(s) and family members - about your wishes and values

Ask Your Agent These Questions

- Will you to the best of your ability:
 - Respect my personal 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 my life?
 - Make sure that what I have asked for is honored?
 - Stay with me even if it gets difficult?

Communicating with a Family Member or Beloved Friend Who ‘Doesn’t want to talk.’”

- Consider recent high profile media cases a ‘teaching’ moment’
- Acknowledge the effect on the family, such as conflict, guilt, anger, law suits
- Ask the question, “Would you want that to happen to your/our family?”

How to Have the Conversation

- Normalize the conversation
- Acknowledge that it is a stressful subject
- Identify the benefits of responsible planning **and**responsible aging:
 - Reduced guilt, uncertainty and conflict
 - Reduced potential for litigation
 - Much higher likelihood your wishes will be honored
 - Requires commitment and conversations

How to Start the Conversation with Loved Ones

- Look for opportunities – after watching a movie, reading a story, or discussing an experience a loved one has had
- Tell your loved ones this is important to you, even if it's difficult to talk about it
- Let them know that it can help to prevent family conflict in the midst of a crisis
- Tell them it's a gift you would like to give them
- Don't expect to resolve everything in one conversation!

How to Talk to Health Care Providers

- Tell your provider this is important to you.
- Provide a copy of your proxy and personal wishes statement for your provider – this may be a way to start the discussion.
- Ask for time to discuss your preferences if you were to become seriously ill - don't wait for your provider to initiate the conversation!
- Discuss specifics of your medical situation.
- Be assertive!

Ask your Physician/Healthcare Provider

- Will you explain realistically what the benefits are versus the burdens of any treatments?
- Will you tell me when it changes - what my prognosis is?
- Would you be willing to continue my care if I chose hospice care?
- 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 treat me as a person, not a disease?

Personal Wishes Statement

If there is no reasonable expectation for my recovery and, in the opinion of my physician, I will die without life sustaining treatment that only prolongs the dying process, I ask that my Health Care Agent consider the following:

_____ **Treatment should be given to maintain my dignity, to keep me comfortable and to relieve pain.**

_____ **If my heart stops, I do not want it to be restarted.**

_____ **If I stop breathing, I do not want to have a breathing tube put into my throat and be hooked up to a breathing machine.**

Personal Wishes Statement

My physician may withdraw or withhold treatment that only serves to prolong the dying process. Some examples of types of such treatment include:

_____ **If I cannot drink, I do not want to receive fluids through a needle placed in my vein, unless necessary to keep me comfortable.**

_____ **If I cannot eat, I do not want a tube inserted in my nose, mouth or surgically placed to give me food.**

_____ **If I have an infection, I do not want antibiotics administered to prolong my life without hope of cure, unless necessary to keep me comfortable.**

Personal Wishes Statement

- _____ If possible, I would like to die at home with hospice care, if needed.
- _____ Unless necessary for my comfort, I would prefer NOT to be hospitalized.
- My faith tradition is _____
- My spiritual contact person is _____
- My faith community is _____
- _____ I wish to have spiritual support.
- _____ I do not wish spiritual support.
- _____ If possible, I wish to be an organ donor.

Checklist

1. I have thought about what is important to me
2. I have chosen my Agent/Alternate
3. I have discussed my wishes and values with my:
 - Agent/Alternate
 - Family members
 - Doctor(s)
 - Spiritual Advisor
 - Attorney

Checklist

cont'd

4. I have completed my Mass. Health Care Proxy form
Signed by 2 witnesses
5. I have completed my Personal Wishes Statement
6. I have given copies to my:
 - Agent/Alternate
 - Family members
 - Doctor(s)
 - Office and Hospital Records
 - Assisted Living Residence and/or Nursing Home
 - Spiritual Advisor
 - Attorney

'A Guide for A Better Ending'

Responsible Aging – Responsible Planning

- Consider Advance Care Planning as important as planning for education, weddings, childbirth, retirement, security, Long Term Care Insurance..
 - Think about who would be at your bedside : include them as you communicate your personal wishes
 - Remember - it should be multigenerational
 - Help others in your family and circle of friends to do their advance care planning – before a crisis!

Resources

- **'Better Ending' website**
 - **'A Guide for a Better Ending' brochure**
 - **'Personal Wishes Statement' and Mass Health Care Proxy**
www.betterending.org or call (508) 767-9877
- **Hospice & Palliative Care Federation of Mass (HPCFM)**
hospicefed@aol.com
www.hospice.org
- **Massachusetts Compassionate Care Coalition (MCCC)**
www.massccc.org
- **Massachusetts End-of-Life Care (MEOLC) 'Resource Guide'**
www.endoflifecommission.org