Understanding the Kentucky Medical Orders for Scope of Treatment (MOST) Form

Who Should Fill Out The KY MOST Form?

If you have a chronic or life limiting illness the Kentucky Medical Orders for Scope of Treatment (MOST) may be for you.

This form will allow you along with your physician to put in writing what your wishes are for your medical treatment.

Not only does it allow you to have in writing what your wishes are for your medical care but it also allows you to express your desires when you want to seek comfort care.

The MOST form will allow your goals and preferences to be respected especially when you are not able to speak for yourself.

The MOST will help your family, caregivers, and power of attorney for health care to make decisions for you when it comes to the difficult choices in stopping or not beginning treatments that will prolong your life.

Important Facts About The MOST Form:

MOST is a medical order that you develop with your doctor.

MOST helps you put in writing what your personal wishes and values for your medical treatment.

MOST expires after one year.

If any section is not filled out on MOST, then for that section full treatment will be given.

If there is conflicting information between your Living Will and MOST, your Living Will will be followed.

The Different Sections Of The MOST Form:

9 out of 10 people said they should have a conversation about their end of life wishes

3 out of 10 people have had a conversation with their loved ones about their end of life wishes

Source: New survey from The Conversation Project, www.theconversationproject.org

Section A: Cardiopulmonary Resuscitation (CPR)

CPR is a medical intervention consisting of a series of rapid, forceful chest compressions and rescue (mouth-to-mouth) breathing. It is used during cardiac arrest, or sudden stoppage of the heart. During cardiac arrest, you have no pulse or heartbeat and you are not breathing. Because the heart is not pumping, blood—which contains vital nutrients and oxygen your body needs—is not circulating and getting to where it needs to go. Too long without these nutrients and oxygen can cause lasing physical damage. CPR is meant to combat it, until your heart starts beating again on its own or death occurs.

Discuss with your doctor the benefits and risks of performing CPR with your certain health condition. As you go through this workbook, keep in mind your goals, beliefs, and values when it comes to certain treatments. In this section, we hope to shed some light on CPR as a medical method, with all the good and the bad.

What Are Some Of The Benefits And Risks Of CPR?

What are some the benefits? The biggest benefit to CPR is the possibility to delay your death. You may be able to spend more time with your loved ones. It can be emotionally reassuring to you and your family that your doctor will do everything he or she can in order to prolong your life.

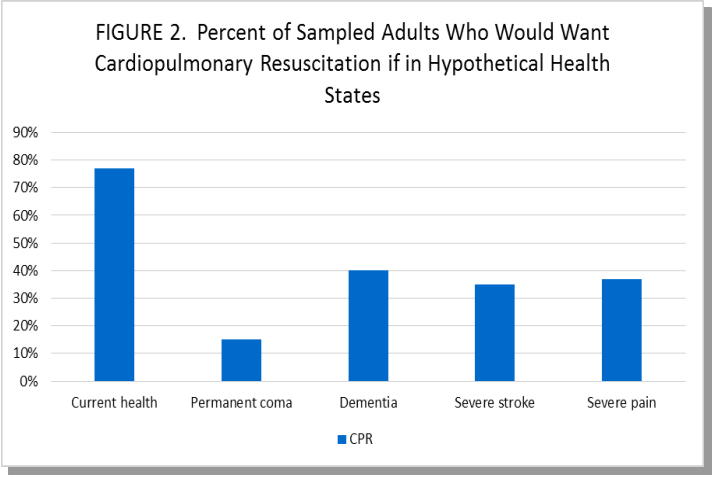
What are some of the risks? There are also many burdens that CPR places on the patient, assuming survival through cardiac arrest. Potential risks of CPR include fractured sternum/ribs, punctured lungs/organs as a result of fractures, aspiration pneumonia (a type of lung infection), internal bleeding, and permanent neurological damage. Broken bones are very painful and take a long time to heal. In the case of pneumonia, antibiotics are most often used to treat it. See Section C for information on making an informed decision regarding antibiotics.

6/10 survivors of CPR will have lasting cognitive problems, including memory and attention span problems, impaired thinking ability, and difficulty in getting tasks done.

1/10 survivors of CPR were in a persistent vegetative state (coma).

3/10 survivors of CPR returned to the condition they were in before.

Source: *Cardio-pulmonary resuscitation: a decision aid for patients and their families.* Retrieved from CARENET.



Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents. Source: Patrick DJ, Pearlman RA, Starks HE, et al. Validation of preferences of life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127:509-17.

Source: Kass-Bartelmes, B. L., & Hughes, R. (2004). Advance Care Planning: Preferences for Care at the End of Life. *Journal of Pain & Palliative Care Pharmacotherapy, 18*(1),

What Are Some Questions That I Need To Consider?

1. I understand that CPR will, at best, return me to the state I was in before. What is important that I am able to do, think, and feel, especially if there are side effects from the procedure?
2. Is CPR anything like how I see it on TV?
3. What treatment will I receive if I choose do-not-resuscitate?
4. What differences in the survival rate of CPR will my condition(s) and prognosis have?

In the general hospital population, the survival rate of CPR is around 15%.

In patients with chronic illnesses, the survival rate of CPR is approximately 10% and decreases with additional illnesses.

In patients who have a terminal diagnosis and are in the ICU, the survival rate of CPR is approximately 2%.

Source: Sehatzadeh, S., Cardiopulmonary resuscitation in patients with terminal illness: an evidence-based analysis. *Ontario Health Technology*

"If the chances. . . for success are so small that it's not worth it, because the negative part of it is so great. . . if a person is gonna take a 10% chance that you're gonna. . . know what's going on, and a 90% chance that you're not going to be able to function normally, that's [extraordinary]."

An 84-year old woman

Rosenfeld, et al.. (2000). End-Of-Life Decision Making: A Qualitative Study of Elderly Individuals. *Journal of General Internal Medicine, 15*, 620-625.

"I thought doctors were supposed to 'do no harm.' Why would they not try to save my life?"

This important conversation is also an emotional one. To even consider refusing what is typically regarded as a life-saving intervention might have you feeling confused, afraid, and maybe even angry. Remember that the options presented in MOST should match *your* preferences, and they are ultimately *your* decisions, not your family's.

Just like any other treatment, it will have benefits and risks associated with it. Similarly, it will be more effective for some patients, and not for others. Survival is not a guarantee of no physical or neurological harm. CPR will, at best, return you the state you were in previously. Are you prepared to continue living like that, and to accept that may be some debilitating burdens?

Section B: Medical Intervention

This section gives you the choice between three types of care you wish to receive. It is important to discuss your treatment options with your doctor to understand your particular health condition so that your values, beliefs, and goals will be respected. These three choices are:

Full Scope of Treatment: goals are to prolong life at all cost. This means being hospitalized if needed and being given full medical treatment to keep you alive, including CPR, intensive care, and life support measures.

Limited Additional Intervention: goals are to provide basic medical treatments. This means no CPR, avoid intensive care, provide medical treatment which may include medications, IV fluids, and comfort measures.

Comfort Measures: goals are to provide comfort care and avoid hospitalizations if possible. This support would include medication to relieve pain and suffering, no CPR or intensive care, and medical intervention that would provide what is needed to meet your end of life wishes including keeping you clean, dry, and warm and allowing you to die where and with whom you want.

Four Questions To Guide Your Goals of Care

Answering these four questions can help you understand what is meaningful to you as you decide what is important for your goal of care for your particular illness. You are encouraged to write down your answers to these questions and discuss them with your doctor. (Please use additional paper if needed)

1. What kind of things are most important to you? What makes you happy?

_____

_____

2. What fears do you have about getting sick or needing medical care?

_____

_____

3. If you were very sick, are there any specific medical treatments that might be too much for you?

_____

_____

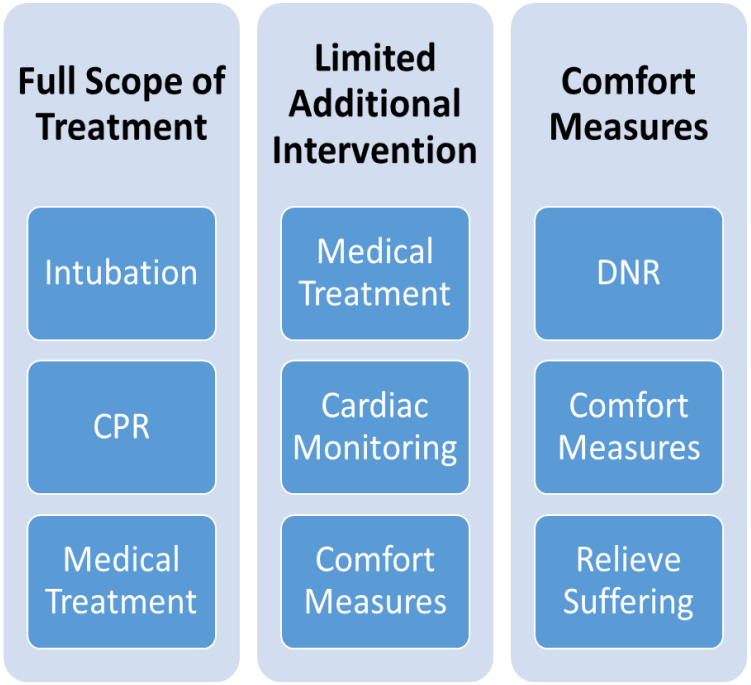
4. Do you have any beliefs that guide you when you make medical decisions?

_____

_____

Source: Volandes, Angelo E.. The Conversation: A Revolutionary Plan for End-of-Life Care (Kindle Locations 1909-1933). Bloomsbury Publishing. Kindle Edition.

Medical Intervention



"More than half of those who have lost someone without ever discussing end-of-life wishes admit that some aspect of the experience could have been improved if they'd had a conversation."

"Those who did have such a conversation had what could be considered a more positive experience in their loved ones' final days — 63% say they felt better knowing they were honoring the wishes of their loved ones, while 39% know their loved one was able to die just the way they wanted."

Source: New survey from The Conversation Project, www.theconversationproject.org

Questions To Ask As The End Of Life Approaches

1. Since the illness is worsening, what will happen next?
2. Why are you suggesting this test or treatment?
3. Will the treatment bring physical comfort?
4. Will the treatment speed up or slow down the dying process?
5. What can we expect to happen in the coming days or weeks?
6. If I or my loved one take this treatment or participate in this clinical trial, will it benefit others in the future?

*Source: End of Life, National Institute of Health, https://nihseniorhealth.gov/endoflife/*preparingfortheendoflife/01.html

Your answers to the questions listed here will help you decide on which goals of care meets your values and beliefs. For example, if your goal is for comfort and you do not want to have CPR, your choice would be Comfort Care. If your goal is to extend your life then Full Scope or Limited Treatment may be your choice. By talking to your doctor about what you want as related to your medical care, your medical decisions can be respected. By choosing to fill out a MOST form, you can help your family respect your wishes especially as related to your end of life care.

Section C: Antibiotics

Antibiotics are medications that help fight infections that are caused by bacteria. They have no effect on viruses such as the common cold, flu, runny nose, or sore throat (World Health Organization). As in Section B, you will want to talk to your doctor about the benefit and burden of using antibiotics for your particular medical condition.

The more you use antibiotics the more likely you will become resistant to that particular medication. There are few types of antibiotics on the market and with the increase in antibiotic resistant bacteria, you will want to have the medication that will be useful for you.

Asking yourself the questions in Section B will help you decide which choice will match your values and beliefs.

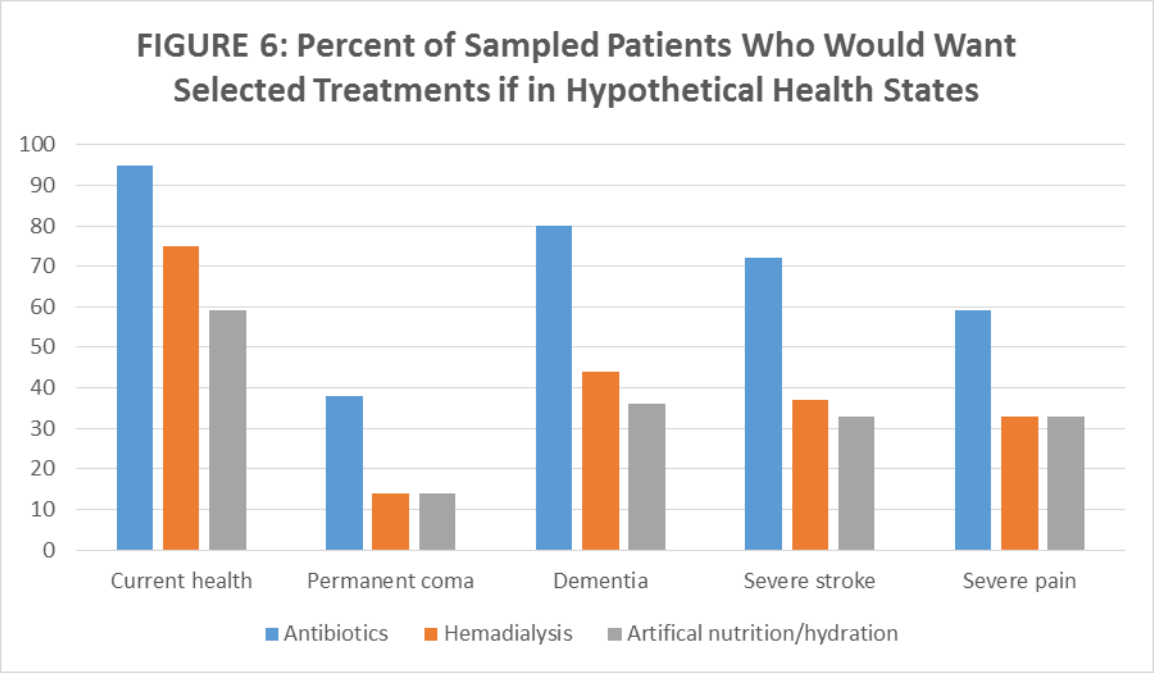
Understanding how antibiotics work will help you decide which box to select in Section C.

> *"If you feel by extraordinary measures you would return her to so-called life, don't do it. . . 'cause what life has she got to go back to, except sitting here. . . in a most undignified way having her [bottom] wiped and wearing a diaper and listening to the screams of the other patients. And this is not the kind of life that my wife would have liked. And so don't do anything in the case she gets bronchitis or pneumonia which is prone to keep her alive."*
>
> "a 92-year-man, reflecting on his decision to withhold antibiotic treatment from his wife, who had severe Alzheimer's disease."
>
> Source: Rosenfeld, et al.. (2000). End-Of-Life Decision Making: A Qualitative Study of Elderly Individuals. *Journal of General Internal Medicine, 15*, 620-625.

What Are Your Preferences Toward Using Antibiotics?

		Strongly Disagree			Strongly Agree	
	Question	**1**	**2**	**3**	**4**	**5**
1	Do you want to take an antibiotic for the purpose of maintaining life?					
2	Do you want to consider the use or limitation of antibiotics when infections occurs?					
3	Do you want to use antibiotics to relieve pain and discomfort?					
4	Do you want to use other measures to relieve symptoms?					

Source: *Kentucky Medical Order for Scope of Treatment Form*, Kentucky Board of Medical Licensure



Sample included 50 well adults ages 21-65 years, 49 well adults older than 65, 49 older adults with chronic illness, 48 adults with terminal cancer, 50 adults with AIDS, 45 stroke survivors, and 50 nursing home residents. Source: Patrick DJ, Pearlman RA, Starks HE, et al. Validation of preferences of life-sustaining treatment: implications for advance care planning. Ann Intern Med 1997;127:509-17.

Source: Kass-Bartelmes, B. L., & Hughes, R. (2004). Advance Care Planning: Preferences for Care at the End of Life. *Journal of Pain & Palliative Care Pharmacotherapy, 18*(1)

Things To Know About Antibiotics

Medicine That Fights Bacterial Infections	Bacterial Infections Are Common to Older People	Side Effects Common With Antibiotics Use	Antibiotic Treatment At End Of Life
•Lower respiratory infections (pneumonia) •Urinary tract infections	•Those who have chronic illness •Those who have a terminal illness	•Digestive Problems •Heart Burn •Bleeding •Fungal Infections	•Antibiotics will not prevent death •Antibiotics may help the person feel more comfortable •Need to weigh benefits against unpleasant side effects.

Source: NIH: National Institute on Aging: End of Life Care: Understanding Healthcare Decision, https://www.nia.nih.gov/health/publication/end-life-helping-comfort-and-care/understanding-healthcare-decisions

Section D: Medically Administered Fluids And Nutrition

Artificial nutrition and hydration (ANH) is a treatment that gives patient food and water through a tube somewhere other than through the mouth. The tube can be inserted intravenously (into a vein, also called IV), nasogastric (through the nose and into the stomach), or enterally (through the stomach). If interested in ANH, your condition and other preferences will determine where ANH is inserted.

You have three options to choose from on the MOST form:

Long-term IV/feeding tube if indicated

IV fluids/feeding tube for a defined trial period

No IV fluids/feeding tubes

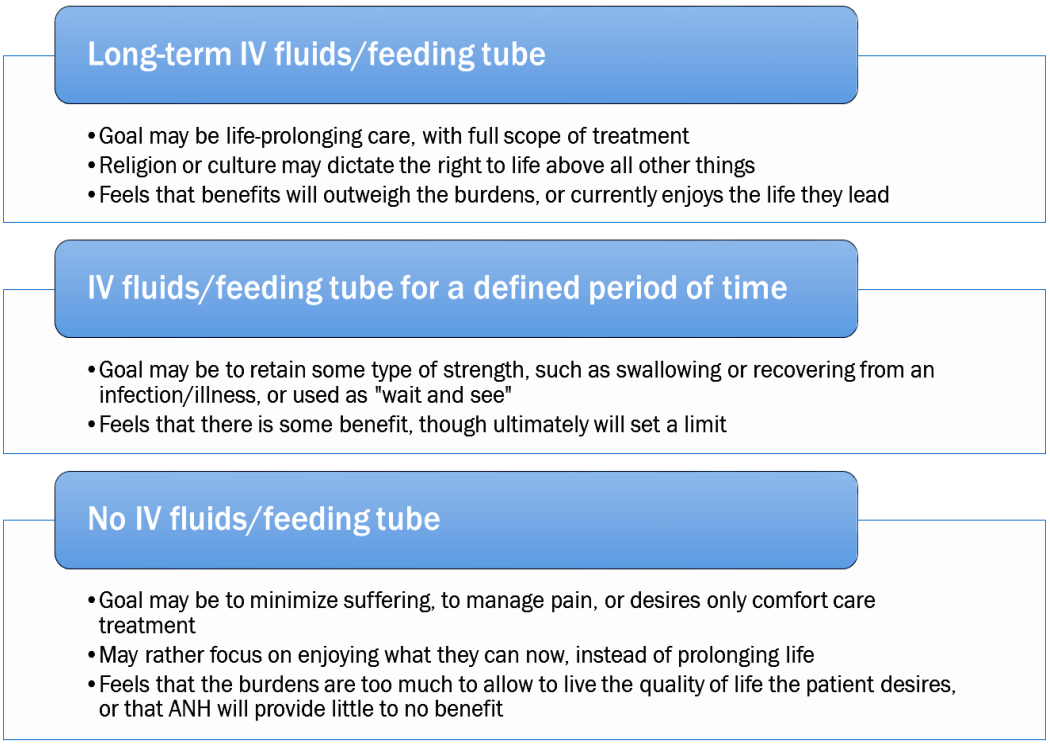
You may choose different options between IV fluids and nutrition through a feeding tube. Special instructions may be written for administration. ANH under a defined trial period will have either a time dictated, in which the tubes are removed when the time is up, or until a certain goal is met.

What Are Your Goals In Using ANH?

If you have already indicated full scope (life-prolonging) care or limited care as defined in Section B, then you may want to utilize ANH as a treatment method. Additionally, if you are unable to swallow, then a trial period of IV fluids/feeding tubes may also be completed. Talk to your doctor about your indications for ANH and if it is an appropriate method for you.

Common goals may include prolonging life; relieving hunger and thirst; maintaining nutritional status; maintaining weight, strength, and endurance; and improving quality of life.

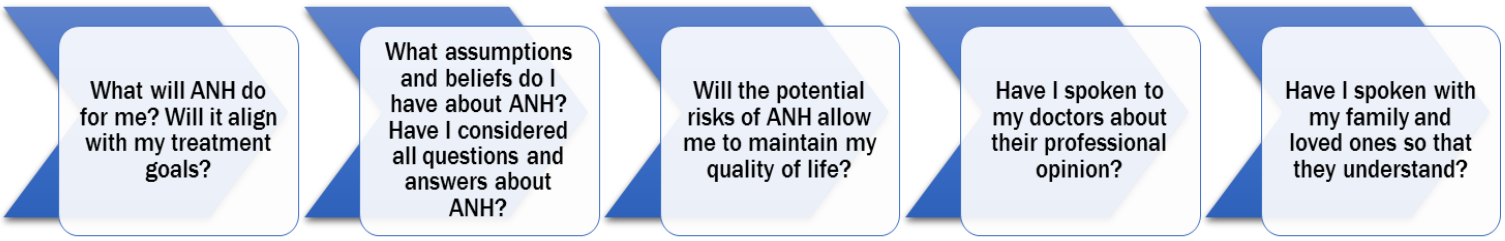
You may have different feelings regarding artificial nutrition vs. artificial hydration, and that is okay! For many, food itself provides an emotional component, and your condition may one day take that away from you.



Source: Mahon, M. (2010). Clinical Decision Making in Palliative Care and End of Life Care. *Nursing Clinics of North America, 45* (1), 345-362. doi:10.1016/j.cnur.2010.03.002

What Are Some Questions That I Need To Consider?

1. What is it like to use ANH?
2. Will I suffer without ANH?
3. Will ANH help relieve hunger and thirst?
4. How long can ANH keep me alive?
5. What treatment options are available if I choose not to begin ANH?
6. Can my family be there to feed me if I choose ANH?
7. What does my religion and culture say about using ANH?



What Are Some Benefits And Risks Of ANH?

There are some physical and emotional burdens associated with ANH. It is up to you to weight the benefits and burdens. Does using ANH allow you to live as you desire? Talk with your doctor for his or her professional opinion on your personal condition and the pros and cons of using this treatment.

Patients using ANH may experience pain and possible infection at the insertion site. Depending on the site, insertion procedure may require anesthesia. Patients may also experience nausea, vomiting, and diarrhea, or pneumonia. Edema/swelling may occur with IV fluid usage.

In an advanced neurodegenerative disease like dementia, the patient will sometimes need restraints to prevent them from pulling out their tubes. This can cause anxiety and agitation, and sometimes pain. Though it is not often, a tube can be inserted incorrectly or be misplaced. This can cause painful skin abrasions and internal bleeding.

However, ANH will also aid you continuing to live, providing your body with the nutrients that it needs to sustain itself. If you are unable to swallow, it is helpful to use until you are able to swallow again, or if you currently enjoy the life you are leading.

Source: Arenella, C. (n.d.). *Artificial Nutrition and Hydration at the End of Life: Beneficial or Harmful?* Retrieved from American Hospice Foundation: https://americanhospice.org/caregiving/artificial-nutrition-and-hydration-at-the-end-of-life-beneficial-or-harmful/

Section E: Patient Preferences As A Basis For The MOST

Section E addresses who will make decisions for you when you are no longer able to make medical decisions for yourself. You have the right to make medical decisions for yourself as long as you are capable. If you become unable to make decisions for yourself, then you can choose someone you trust and care for to make your healthcare decisions.

There are two types of advance directives that are recognized under Kentucky law that allow you to choose who has the right to make decisions for you when you are unable. These two laws are the ***living will*** (KRS 311.625) and ***powers of health care surrogate*** (KRS 311.629). A living will allows you put into writing your wishes for end of life care, and the powers of health care surrogate allows you to choose who you want to make your healthcare decisions (KY Living Will Packet).

A ***power of attorney*** is another type of advance directive similar to the powers of health care surrogate but may also give someone powers to make personal and financial decisions that go beyond making your medical decisions. Kentucky does not have a standard form for the power of attorney.

If you do not choose someone to make medical decisions for you when you become unable to do so, then Kentucky has a law that lists an order of who will be able to make decisions on your behalf. This person may or may not be who you want to make your medical decisions. This law is ***the responsible parties authorized to make health care decisions*** (KSR 311.631) which lists an order of who will be able to make decisions for you when you cannot make medical decisions for yourself. This order is listed in Section E of the MOST form. You may check the appropriate box.

It is very important that any advance medical directives you have filled out matches your values, beliefs, and goals you have filled out on Sections A, B, C, and D. It is also important to know that your living will shall prevail over your MOST form if they disagree.

How Do I Choose A Heath Care Surrogate?

1. Choose a health care surrogate who understands your goals, values, beliefs, and wishes.
2. Choose a health care surrogate who will act on your wishes.
3. Choose a health care surrogate who will be available when you need him or her.

Source: Volandes, Angelo E.. *The Conversation: A Revolutionary Plan for End-of-Life Care (Kindle Locations 2045-2062). Bloomsbury Publishing. Kindle Edition.*

Important Qualities in Choosing a Heath Care Surrogate:

- Will they respect your values, wishes, and beliefs?
- Are they someone you trust and cares for you?
- Can they make difficult decisions in stressful conditions?

Most Import Factors for People at End of Life

Source: Final Chapter: Californians' Attitudes and Experiences with Death and Dying. (2012). Retrieved from California Healthcare Foundation: http://www.chcf.org/publications/2012/02/final-chapter-death-dying

Who Will Decide For You?

The following order of persons who will make decisions in Kentucky if you do not choose someone to be your Health Care Surrogate will be in order of priority as follows:

1. The judicially-appointed guardian of patient
2. The attorney-in-fact named in a durable power of attorney
3. The spouse of the patient
4. Majority of adult child of the patient
5. The parents of the patient
6. The nearest living relative of the patient

Source: 311.631 Responsible parties authorized to make health care decisions. (2017, April 11). Retrieved from Ky.gov: http://www.lrc.ky.gov/Statutes/statute.aspx?id=30567

After Reading The MOST Guide

		Strongly Disagree			Strongly Agree	
	Questions	**1**	**2**	**3**	**4**	**5**
1	I will talk about my medical concerns with my doctor.					
2	I will choose who I want to make medical decisions for me when I become unable to make those decisions for myself.					
3	I will fill out the MOST Form with my doctor.					
4	I will certify my MOST form is in accordance with the decisions in my current advance directive..					

Resources

Cardiopulmonary Resuscitation Understanding

- CPR Decision Aid (YouTube)

Medical Interventions

- THE CONVERSATION by Angelo E. Volandes, M.D. (YouTube)
- Extremis, Director: Dan Krauss, 2016, Netflix Documentary
- Tricia's Story: Goals-based Discussions & Time-Limited Trials (YouTube)

Antibiotics

- Antibiotics—What You Need to Know (YouTube)
- WHO 5 things you need to know about antibiotics (YouTube)
- Discussion Antibiotics with Dr. Mary Ann Bauman (YouTube)

Artificial Nutrition/Hydration

- End of life care Chapter 5 Medication and nutrition (YouTube)
- Discussing Feeding Tubes & Artificial Nutrition & Hydration (YouTube)

Advance Directives

- What are Advance Directives?, NIH Senior Health (YouTube)

Websites

- The Conversation Project
- Caring Info, National Hospice and Palliative Care Organization
- End-of-Life legal instruments, National Institute on Aging
- Kentucky Living Will Packet
- Kentucky Medical Order for Scope of Treatment

Videos:

Antibiotics - What You Need To Know . (2014, July 21). Retrieved from Rehealthify : https://www.youtube.com/watch?v=P665Slcmd8o

Antibiotics: the 5 things everyone needs to know . (2012, November 13). Retrieved from WHO Regional Office for Europe : https://www.youtube.com/watch?v=ndqxlfRY43c

CPR Decision Aid. (2016, September 8). Retrieved from Carenet: https://www.youtube.com/watch?v=aE6bmNTUe5E

Discussing Antibiotics with Dr. Mary Ann Bauman . (2013, August 19). Retrieved from INTEGRIS : https://www.youtube.com/watch?v=Bj3SC8KxBoo

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End of life care Chapter 5 Medication and Nutrition . (2016, January 14). Retrieved from Work Train : https://www.youtube.com/watch?v=OEY_TexmaAo

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