Advance Care Planning Workbook

Making Your Healthcare Wishes Known

Hudson Valley Hospice

hvhospice.org/acp

Making Your Healthcare Wishes Known

At any age, an illness or severe injury can leave someone too ill to make his or her own health care decisions. We encourage everyone who is 18 or older to participate in Advance Care Planning before a medical crisis occurs. This workbook includes questions to help you make decisions about the kind of care you would or would not want to receive. It is our hope that it will help prepare you and your loved ones should a challenging circumstance arise.

What Is Advance Care Planning?

Advance Care Planning focuses on learning about:

- The types of decisions that might need to be made if a medical crisis occurs;
- Thinking about what you would want;
- Choosing someone to speak for you if you are unable, referred to as your *Health Care Proxy*. Are they willing to be your health care agent and honor **your** wishes, even if they do not agree with them;
- Having the conversations with your Health Care Proxy and other loved ones; and
- Documenting who that person is and your wishes.

Everyone is encouraged to complete a Health Care Proxy Form to document who they have chosen to speak for them if they are unable to and help guide their Health Care Proxy through any decisions that may need to be made. It should be updated every few years because your situation, goals and wishes may change over time. You can make changes to this document at any time.

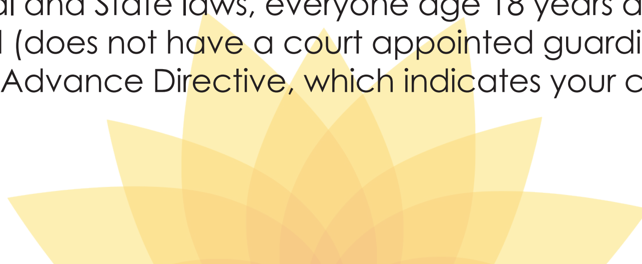
What Is An Advance Directive?

Advance Directives are state specific legally binding documents that allow you to designate who will advocate and speak for you if you are ever unable to speak for yourself. *Your Health Care Proxy is only authorized to make medical treatments on your behalf if/when you are unable to speak for yourself.*

Examples of Advance Directive documents in New York State include the New York State Health Care Proxy, Living Will, Power of Attorney and MOLST (Medical Orders for Life Sustaining Treatment). The NYS Health Care Proxy and Living Will only needs to be witnessed by two people that are not the designated Health Care Proxy, a relative, your health care provider or insurer or someone responsible for your finances. They do not need to be notarized. The MOLST is completed with and signed by your doctor.

Why Do I Need An Advance Directive?

Your choices matter and you have a right to make your own decisions if there comes a time when you cannot understand or are unable to express your choices due to an illness or accident. Under Federal and State laws, everyone age 18 years and older who is legally competent of sound mind (does not have a court appointed guardian for medical choices) has the right to create an Advance Directive, which indicates your choices for medical care.



Why Does Making Your Medical Wishes Known Matter?

- Your wishes cannot be honored if no one knows what they are.
- Knowing your wishes takes a heavy burden off your loved ones. This means they will not have to make difficult decisions while trying to guess what you would want.
- Studies show that people suffer from post-traumatic stress disorder when they do not know their loved one's wishes and are placed in a decision-making role.
- A sudden turn in a life threatening or limiting illness or a high anxiety, loud, fast-paced Emergency Room is not a good place to start this conversation.
- The time to start the conversation is now, before you need medical care.

Why Don't People Make Their Medical Wishes Known?

There are as many reasons as there are people. Here are some common ones:

- I am not sick enough.
- My family members have different opinions.
- I don't think this will ever happen to me.
- I am not sure what to say, or how to start the conversation with my loved ones.
- It's too upsetting to think about.
- I am not sure where to begin.
- I am young and healthy.

Who Should I Pick As A Health Care Proxy?

It's important to pick the right person to be your health care agent. Select someone who:

- Is 18 years of age or older who you trust with your life.
- Knows you well and understands what is important to you.
- Is willing to follow your instructions.
- Would be strong enough to act on your wishes, separate from his or her own feelings.
- Would be able to handle conflicting opinions that might arise with family members, friends, and medical clinicians regarding your choices.

What Will My Health Care Proxy Be Expected To Do?

- Communicate with your health care team about what your answers to medical questions would be if you could give them.
- Answer questions from the health care team about the kind of care you would or would not want in certain situations.
- Consent to or refuse medical treatments for you, including life-sustaining treatment.
- Authorize your transfer to other facilities if needed (nursing home, another physician, another hospital)
- **Your health care agent only directs care when you cannot.**

Seven Steps to Making Your Wishes Known

Step 1: Organize Your Thoughts
Think about what is important to you and utilize the Quality of Life Assessment and My Treatment Wishes Worksheets and the End of Life Planning Guide tools that are included. These will help you think about what you want and get ready for the conversations with your Health Care Proxy and loved ones.

List important things in your life that matter to you:

________________________ ________________________ ________________________

What activities would you not want to live without:

________________________ ________________________ ________________________

I would not want to live under the following conditions:

________________________ ________________________ ________________________

Step 2: Decide When and Where to have the Conversation with your Health Care Proxy and those closest to you to ensure everyone understands and will honor your wishes.

WHO to talk with
Mom or Dad
Child/Children
Spouse/Partner
Sister/Brother
Doctor/Caregiver
Faith Leader
Other: ______________

WHERE to talk
At the kitchen table
Sitting in the park
On a walk
In the car
At a restaurant
At a friend's house
In the living room
At church
Other: ______________

WHEN to talk
At the next holiday
Before my child goes to college
Before I get sick again
Before I have surgery
At a family gathering
After church
Other: ______________

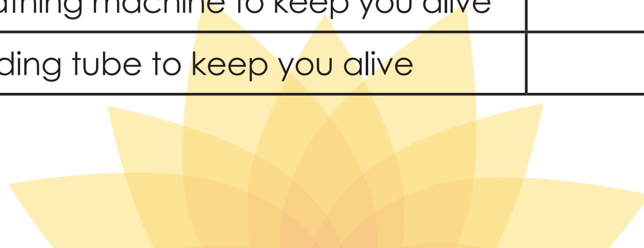
Step 3: Have the Conversations, Explain your Wishes, Complete a Health Care Proxy Form and have it Witnessed. A copy is included herein or you can download it at hvhospice.org/end-of-life-planning. The state of New York requires you to sign the document in front of two witnesses. Your witnesses cannot be:

- Your health care agent(s)
- Your health care provider or employer of your health care provider
- Related to you by blood, marriage or adoption
- Financially responsible for costs associated to your health care
- An employee of life or health insurance provider for this person.

Quality of Life Assessment Worksheet

If you were faced with an illness that significantly impacted your quality of life values, please indicate which of the following is worth living, barely worth living, or not worth living.

If you... ..life would be	Worth Living	Barely Worth Living	Not Worth Living	Unsure
Could not think clearly and were confused most of the time				
Could no longer make your own decisions most of the time				
Had discomforts such as nausea, diarrhea or shortness of breath most of the time				
Had severe pain or discomfort most of the time				
Could no longer contribute to your family's well-being				
Were no longer able to go out for social activities such as church, shopping, and visiting others				
Could not communicate in a way that people could understand you				
Were confined to a wheelchair most of the day				
Could no longer be spoon fed safely and needed to be fed via a tube				
No longer recognize your family members or loved ones				
Were a severe financial burden on your family				
Could not feed yourself and needed to have others feed you most of the time				
Were no longer able to talk and be understood by others				
Needed someone else to bathe you and or get you dressed each day				
Needed someone to care for you 24 hours a day				
Lost your mobility and could no longer get out of bed on your own				
Were paralyzed, but could think clearly				
Needed to rely on a breathing machine to keep you alive				
Needed to rely on a feeding tube to keep you alive				



My Treatment Wishes Worksheet

Please check the box indicating your wishes for treatment in each situation:

I would prefer to:	Agree	Disagree	Unsure
Be told the truth about my condition, no matter how "bad" the news			
Be told first, rather than my family about my condition and treatment			
Have my wishes to refuse medical treatment be honored, even if it may shorten my life or result in my death			
Have my pain or discomforts lessened, even if the dose of medicine would make me less aware or sleepy			
Have all treatments possible to keep me alive, even if I will never get better			
Die at home rather than in a hospital or nursing home			
Be allowed to die comfortably and free of machines if there is little hope for a meaningful recovery			
If I were close to death, I would not want artificial nutrition or hydration given just to keep my body functioning			
Have treatments based on the goal of helping me to get better so I can live a life consistent with my values and wishes. I want those treatments withdrawn or stopped when I can no longer achieve these goals			

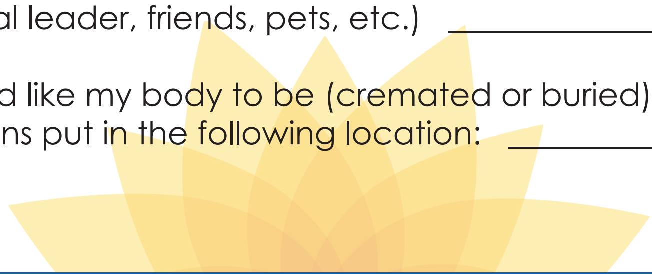
End-of-Life Planning Guide

1. What are your fears, if any, regarding the end of your life? ______________________________
____
____

2. If I were very ill and given less than a year to live, I would want to have palliative or hospice care made available to ensure I was comfortable and that my symptoms were managed. Yes _____ No _____

3. If I were dying, I would like to be (at home, hospital, our Hospice House etc.) ____________ with my (family, spiritual leader, friends, pets, etc.) ______________________________

4. After my death, I would like my body to be (cremated or buried) ______________________ and my body or remains put in the following location: ______________________________.



5. If I had severe pain, I would want to receive adequate pain medications to control it, even if it makes me drowsy or puts me to sleep most of the time. Yes _____ No _____

If I could plan it today, the last days or weeks of my life would look like this: __________________

____

____

____

____

Step 5: Store Your Document

Keep the original document and email a copy to your health care agent.

- Make a physical copy for your health care agent(s) to keep as well.
- Make a physical copy for your physician to keep and discuss it with him or her.

Step 6: Make This Conversation a Part of Your Life

You can make changes to your advance medical directive at any time. We recommend you update your document every few years or follow the 5D rule:

- Every new **decade** of your life
- After the **death** of a loved one
- After a **divorce**
- After any significant **diagnosis**
- After any significant **decline** in functioning

Step 7: Congratulate Yourself!

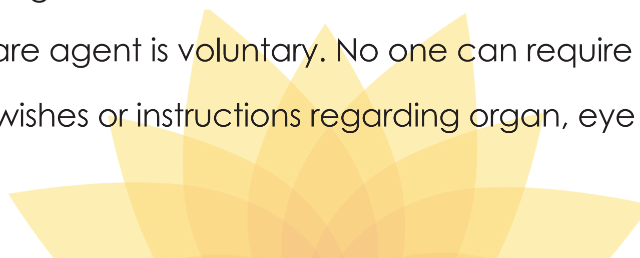
You have made your wishes known and provided your loved ones with one of the best gifts you could ever give them. Be proud of yourself, this wasn't an easy thing to do.

For more information, contact Hudson Valley Hospice at **845-485-2273** or email **info@hvhospice.org**.

New York State Health Care Proxy Form

The Health Care Proxy Form is an important legal document. Before signing, you should understand the following facts:

1. This form gives the person you choose as your agent the authority to make all health care decisions for you, including the decision to remove or provide life-sustaining treatment, unless you say otherwise in this form. "Health care" means any treatment, service or procedure to diagnose or treat your physical or mental condition.
2. Unless your agent reasonably knows your wishes about artificial nutrition and hydration (nourishment and water provided by a feeding tube or intravenous line), he or she will not be allowed to refuse or consent to those measures for you.
3. Your agent will start making decisions for you when your doctor determines that you are not able to make health care decisions for yourself.
4. You may write on this form examples of the types of treatments that you would not desire and/or those treatments that you want to make sure you receive. The instructions may be used to limit the decision-making power of the agent. Your agent must follow your instructions when making decisions for you.
5. You do not need a lawyer to fill out this form.
6. You may choose any adult (18 years of age or older), including a family member or close friend, to be your agent. If you select a doctor as your agent, he or she will have to choose between acting as your agent or as your attending doctor because a doctor cannot do both at the same time. Also, if you are a patient or resident of a hospital, nursing home or mental hygiene facility, there are special restrictions about naming someone who works for that facility as your agent. Ask staff at the facility to explain those restrictions.
7. Before appointing someone as your health care agent, discuss it with them to make sure that they are willing to act as your agent. Tell the person you choose that they will be your health care agent. Discuss your health care wishes and this form with your agent. Be sure to give them a signed copy. Your agent cannot be sued for health care decisions made in good faith.
8. If you have named your spouse as your health care agent and you later become divorced or legally separated, your former spouse can no longer be your agent by law, unless you state otherwise. If you would like your former spouse to remain your agent, you may note this on your current form and date it or complete a new form naming your former spouse.
9. Even though you have signed this form, you have the right to make health care decisions for yourself as long as your are able to do so, and treatment cannot be given to you or stopped if you object, nor will your agent have any power to object.
10. You may cancel the authority given to your agent by telling him or her or your health care provider orally or in writing.
11. Appointing a health care agent is voluntary. No one can require you to appoint one.
12. You may express your wishes or instructions regarding organ, eye and/or tissue donation on this form.



Health Care Proxy Form Instructions

Item (1)
Write the name, home address and telephone number of the person you are selecting as your agent.

Item (2)
If you want to appoint an alternate agent, write the name, home address and telephone number of the person you are selecting as your alternate agent.

Item (3)
Your Health Care Proxy will remain valid indefinitely unless you set an expiration date or condition for its expiration. This section is optional and should be filled in only if you want your Health Care Proxy to expire.

Item (4)
If you have special instructions for your agent, write them here. Also, if you wish to limit your agent's authority in any way, you may say so here or discuss them with your health care agent. If you do not state any limitations, your agent will be allowed to make all health care decisions that you could have made, including the decision to consent to or refuse life-sustaining treatment.

If you want to give your agent broad authority, you may do so right on the form. Simply write: I have discussed my wishes with my health care agent and alternate and they know my wishes including those about artificial nutrition and hydration.

If you wish to make more specific instructions, you could say:

If I become terminally ill, I do/don't want to receive the following types of treatments....

If I am in a coma or have little conscious understanding, with no hope of recovery, then I do/don't want the following types of treatments:....

If I have brain damage or a brain disease that makes me unable to recognize people or speak and there is no hope that my condition will improve, I do/don't want the following types of treatments:....

I have discussed with my agent my wishes about______________ and I want my agent to make all decisions about these measures.

Examples of medical treatments about which you may wish to give your agent special instructions are listed below. This is not a complete list:

- artificial respiration
- artificial nutrition and hydration (nourishment and water provided by feeding tube)
- cardiopulmonary resuscitation (CPR)
- antipsychotic medication
- electric shock therapy
- antibiotics
- surgical procedures
- dialysis
- transplantation
- blood transfusions
- abortion
- sterilization

Item (5)
You must date and sign this Health Care Proxy form. If you are unable to sign yourself, you may direct someone else to sign in your presence. Be sure to include your address.

Item (6)
You may state wishes or instructions about organ, eye and /or tissue donation on this form. New York law does provide for certain individuals in order of priority to consent to an organ, eye and/or tissue donation on your behalf: your designated health care agent/proxy; your designated agent to control the disposition of your remains; your spouse, if you are not legally separated, or your domestic partner; a son or daughter 18 years of age or older; either of your parents; a brother or sister 18 years of age or older; an adult grandchild; a grandparent; a guardian appointed by a court prior to your death; or any other person authorized to dispose of your body.

Item (7)
Two witnesses 18 years of age or older must sign this Health Care Proxy form. The person who is appointed your agent or alternate agent cannot sign as a witness.

HEALTH CARE PROXY

(1) I, ____

hereby appoint ____

(name, home address and telephone number)

____

____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

(2) Optional: Alternate Agent

If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint ____

(name, home address and telephone number)

____

____

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (*Optional: If you want this proxy to expire, state the date or conditions here.)* This proxy shall expire *(specify date or conditions):*

____

____

(4) Optional: I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. *(If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here.)* I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions *(attach additional pages as necessary):*

____

____

In order for your agent to make health care decisions for you about artificial nutrition and hydration *(nourishment and water provided by feeding tube and intravenous line),* your agent must reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.

(5) Your Identification *(please print)*

Your Name ______________________________

Your Signature ______________________________ Date ______________

Your Address ______________________________

(6) Optional: Organ, Eye and/or Tissue Donation

I hereby make an anatomical gift, to be effective upon my death, of:
(check any that apply)

☐ Any needed organs, eyes and/or tissues

☐ The following organs, eyes and/or tissues ______________________________

____

☐ Limitations ______________________________

If you do not state your wishes or instructions about organ, eye and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or prevent a person, who is otherwise authorized by law, to consent to a donation on your behalf.

Your Signature ______________________________ Date ______________

(7) Statement by Witnesses *(Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)*

I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.

Witness 1

Date ______________________________

Name *(print)* ______________________________

Signature ______________________________

Address ______________________________

____

Witness 2

Date ______________________________

Name *(print)* ______________________________

Signature ______________________________

Address ______________________________

____

Department of Health

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