# YOUR LIFE.

# YOUR WAY.

Main Line HealthCare
Physician Network

# INTRODUCTION

## YOUR LIFE. YOUR WAY.

If you are over 18 years old, we advise you to create an advance care plan even if you are healthy. An advance care plan states your wishes about your future medical care. It is used if you are unable to speak for yourself due to injury, illness or disease.

**75 PERCENT OF PEOPLE HOSPITALIZED WITH LIFE-THREATENING ILLNESS CANNOT MAKE DECISIONS ABOUT THEIR CARE AND NEED SOMEONE ELSE TO MAKE DECISIONS FOR THEM.**

This is called a "surrogate decision maker."

Studies also show that such responsibility can be very stressful and upsetting for surrogate decision makers. Having an advance care plan can make difficult medical decisions easier. It is truly a gift you give your loved ones. We hope this six-step approach will simplify your advance care planning. Please note we have also included (after Step 3 in this folder) a blank advance directive for your convenience.

# STEP 1

## THINK ABOUT YOUR VALUES AND WISHES

We usually don't think about a time when we cannot speak for ourselves. But what would it be like if you were badly injured or sick? How would it affect your family and loved ones?

**THIS STEP GETS YOU THINKING ABOUT WHAT'S IMPORTANT TO YOU.** You think about the kind of care you would want in certain situations. Take a moment to read and reflect on each scenario below. Initial the box that is most like what you would want in each situation. It's okay to mark "I don't know" if you're unsure at this point. Once you've initialed after each one, you can do the same in your advance directive document (Step 3).

| IF I AM IN THESE SITUATIONS: | I want to continue living like this | I'm not sure | I do not want to live like this |
|---|---|---|---|
| Cannot understand what I read or cannot carry on a conversation due to dementia or brain injury | | | |
| Need to stay in a nursing home for the rest of my life | | | |
| Need somebody to take care of me (bathing, feeding, using the bathroom, and getting dressed) for the rest of my life | | | |
| Can't go outside on my own for the rest of my life | | | |

# STEP 2

## NAME YOUR SURROGATE DECISION MAKER

**THIS IS AN IMPORTANT CHOICE.** The person you choose will need to make difficult medical decisions for you if you cannot understand your condition or express yourself. Other names for this person are "health care agent" or "health care power of attorney."

Usually it is someone close to you. It could be your spouse or partner, sibling, close friend, clergy or another trusted person. Once you pick a surrogate decision maker, talk with them. Make sure the person is willing and able to accept the responsibility. You can always change your mind later. If something changes, you can name a different surrogate decision maker by updating your advance care document.

### WHAT HAPPENS IF I DON'T HAVE A SURROGATE?

In Pennsylvania, if you do not have a surrogate, the order of decision making for your care goes as follows:

1. Your spouse (unless divorce is pending) and your adult children who are not the children of your spouse
2. Your adult child
3. Your parent
4. Your adult brother or sister
5. Your adult grandchild
6. An adult who has some knowledge of your preferences and values

If none of these are available, a guardian may need to be appointed by a court to become your health care decision maker.

# STEP 3

## COMPLETE AN ADVANCE DIRECTIVE DOCUMENT

***BEFORE YOU START THIS STEP, PLEASE BE SURE TO COMPLETE STEPS 1 AND 2.***

**AN ADVANCE DIRECTIVE IS A WRITTEN LEGAL DOCUMENT** that explains your wishes and/or who you would like to make decisions for you if you cannot communicate for yourself. In Pennsylvania, an advance directive can be a living will, a health care power of attorney, or a combination document.

We have provided a blank advance directive document for you. Please complete each section. The document requires signature by you and two witnesses. Keep in mind, this advance directive will only be used:

- If you cannot make health care decisions for yourself
- For medical and health care decisions (not for financial or personal affairs)

*This advance directive document does NOT give orders to emergency personnel. See Step 4 for information about additional emergency documents.*

### UNDERSTAND THE DIFFERENT SECTIONS OF THE ADVANCE DIRECTIVE

As you read and complete your advance directive, you may refer to the definitions for a better understanding of these terms:

**End-stage medical condition**
**Health care power of attorney**
**Health care agent**
**Life-sustaining treatment**
**Living will**
**Organ donation**
**Permanently unconscious**

# DEFINITIONS

**ADVANCE DIRECTIVE:** A legal document(s) that tells others your medical care preferences and/or whom you would like to make decisions for you if you are unable to speak for yourself. Also called health care power of attorney or living will or a combination document.

**CPR/CARDIOPULMONARY RESUSCITATION:** Any of the following procedures:

- Cardiac compression
- Invasive airway technique
- Artificial ventilation
- Defibrillation

**END-STAGE MEDICAL CONDITION:** A medical problem in an advanced state that will eventually cause death and cannot be cured. This problem may be caused by injury or disease.

**HEALTH CARE AGENT:** A person chosen by you to make health care decisions in case you are unable to do so yourself.

**HEALTH CARE POWER OF ATTORNEY:** A written legal document that names another person (your health care agent) to make health care decisions for you when you can't speak for yourself. This document does not impact bills or other financial matters.

**INCOMPETENT:** You may be declared incompetent if you are unable to do each of these:

- Understand your medical problems and treatment options
- Make a treatment decision
- Tell your decision to someone else

**LIFE-SUSTAINING TREATMENT:** Any medical procedure or intervention that is intended to maintain the current clinical condition of a patient. When life-sustaining treatment is given to a patient who has an end-stage medical condition or is permanently unconscious, the treatment will serve only to prolong the process of dying or maintain the patient in a state of permanent unconsciousness.

In the case of a patient with an advance directive or order, life-sustaining treatment may include nutrition (food) and hydration (water) given by gastric tube (through the stomach) or intravenously (through the veins), as well as any other artificial or invasive means indicated by the order or directive.

**LIVING WILL:** A written legal document stating your wishes for health care if you are in an end-stage medical condition or are permanently unconscious. It is used if you are too sick to state your wishes.

# DEFINITIONS

**ORGAN DONATION:** You may specify in your advance directive whether you consent (agree) or decline (do not want) to donate your organs and tissues at the time of your death for the purpose of transplant, medical study or education.

**OUT-OF-HOSPITAL DNR (DO NOT RESUSCITATE):** An order as set forth in section 5484 of the Pennsylvania Code and provided to you by your attending physician. The DNR directs emergency medical services providers to withhold resuscitation in the event you have respiratory or cardiac arrest outside of a hospital.

**PATIENT:** An individual who has a medical condition.

**PERMANENTLY UNCONSCIOUS:** A medical problem causing loss of consciousness and no ability to interact with the environment. This problem cannot be cured or made better. Irreversible vegetative state and irreversible coma are two examples.

**POLST:** A set of medical orders that communicates what kind of treatment you want to receive towards the end of life.

**SEVERE BRAIN DAMAGE:** An irreversible (will not change or go back) condition that significantly affects brain function.

**TUBE FEEDINGS:** Nutrition administered by gastric tube or other artificial or invasive means.

In your living will, you can indicate whether you want nutrition (food) or hydration (water) medically supplied by a tube into your nose, stomach, intestine, arteries, or veins in the event you have an end-stage medical condition or are permanently unconscious and there is no realistic hope of significant recovery.

# Durable Health Care Power of Attorney

I _____, of _____ County, Pennsylvania, appoint the person named below to be my health care agent to make health and personal care decisions for me.

Effective immediately and continuously until my death or revocation by a writing signed by me or someone authorized to make health care treatment decisions for me, I authorize all health care providers or other covered entities to disclose to my health care agent, upon my agent's request, any information, oral or written, regarding my physical or mental health, including, but not limited to, medical and hospital records and what is otherwise private, privileged, protected or personal health information, such as health information as defined and described in the Health Insurance Portability and Accountability Act of 1996 (Public Law 104—191, 110 Stat. 1936), the regulations promulgated thereunder and any other State or local laws and rules. Information disclosed by a health care provider or other covered entity may be redisclosed and may no longer be subject to the privacy rules provided by 45 C.F.R. Pt. 164.

The remainder of this document will take effect when and only when I lack the ability to understand, make or communicate a choice regarding a health or personal care decision as verified by my attending physician. My health care agent may not delegate the authority to make decisions.

My health care agent has all of the following powers subject to the health care treatment instructions that follow in Part III (cross out any powers you do not want to give your health care agent):

1 To authorize, withhold or withdraw medical care and surgical procedures.

2 To authorize, withhold or withdraw nutrition (food) or hydration (water) medically supplied by tube through my nose, stomach, intestines, arteries or veins.

3 To authorize my admission to or discharge from a medical, nursing, residential or similar facility and to make agreements for my care and health insurance for my care, including hospice and/or palliative care.

4 To hire and fire medical, social service and other support personnel responsible for my care.

5 To take any legal action necessary to do what I have directed.

6 To request that a physician responsible for my care issue a do-not-resuscitate (DNR) order, including an out-of-hospital DNR order, and sign any required documents and consents.

## Appointment of Health Care Agent

I appoint the following health care agent:

Health Care Agent (Name and relationship): _____

Address: _____

Telephone Number: Home _____ Work _____

E-Mail: _____

If you do not name a health care agent, health care providers will ask your family or an adult who knows your preferences and values for help in determining your wishes for treatment. Note that you may not appoint your doctor or other health care provider as your health care agent unless related to you by blood, marriage or adoption.

If my health care agent is not readily available or if my health care agent is my spouse and an action for divorce is filed by either of us after the date of this document, I appoint the person or persons named below in the order named. (It is helpful, but not required, to name alternative health care agents.)

First Alternative Health Care Agent (name and relationship):_____

Address: _____

Telephone Number: Home_____ Work _____

E-Mail: _____

Second Alternative Health Care Agent (name and relationship):_____

Address: _____

Telephone Number: Home_____ Work _____

E-Mail: _____

## Guidance for Health Care Agent Goals

If I have an end-stage medical condition or other extreme irreversible medical condition, my goals in making medical decisions are as follows (insert your personal priorities such as comfort, care, preservation of mental function, etc.):

_____
_____
_____
_____
_____
_____

In order to help understand what you want from medical treatment, place your initials in the box which reflects your values. Remember that these are used only to help inform your physician and guide your Health Care Agent in making health care decision if you are not able to communicate your wishes:

| If I am in these situations: | I want to continue living like this | I'm not sure | I do not want to live like this |
|---|---|---|---|
| Cannot understand what I read or cannot carry on a conversation due to dementia or brain injury. | | | |
| Need to stay in a nursing home for the rest of my life. | | | |
| Need somebody to take care of me (bathing, feeding, using the bathroom, and getting dressed) for the rest of my life. | | | |
| Can't go outside on my own for the rest of my life. | | | |

## Severe Brain Damage or Brain Disease

If I should suffer from severe and irreversible brain damage or brain disease with no realistic hope of significant recovery, I would consider such a condition intolerable and the application of aggressive medical care to be burdensome. I therefore request that my health care agent respond to any intervening (other and separate) life-threatening conditions in the same manner as directed for an end-stage medical condition or state of permanent unconsciousness as I have indicated below.

Initials I agree _____

Initials I disagree _____

## Health Care Treatment Instructions in the Event of End-Stage Medical Condition or Permanent Unconsciousness

## (Living Will)

The following health care treatment instructions exercise my right to make my own health care decisions. These instructions are intended to provide clear and convincing evidence of my wishes to be followed when I lack the capacity to understand, make or communicate my treatment decisions:

If I have an end-stage medical condition (which will result in my death, despite the introduction or continuation of medical treatment) or am permanently unconscious such as an irreversible coma or an irreversible vegetative state and there is no realistic hope of significant recovery, all of the following apply (cross out any treatment instructions with which you do not agree):

1 I direct that I be given health care treatment to relieve pain or provide comfort even if such treatment might shorten my life, suppress my appetite or my breathing, or be habit forming.

2 I direct that all life-prolonging procedures be withheld or withdrawn.

3 I specifically do not want any of the following as life prolonging procedures: (If you wish to receive any of these treatments, write "I do want" after the treatment)

heart-lung resuscitation (CPR)_____
mechanical ventilator (breathing machine) _____
dialysis (kidney machine) _____
surgery _____
chemotherapy_____
radiation treatment _____
antibiotics _____

Please indicate whether you want nutrition (food) or hydration (water) medically supplied by a tube into your nose, stomach, intestine, arteries, or veins if you have an end-stage medical condition or are permanently unconscious and there is no realistic hope of significant recovery. (Initial only one statement).

## Tube Feedings

_____I want tube feedings to be given

## No Tube Feedings

_____I do not want tube feedings to be given.

## Health Care Agent's Use of Instructions
## (Initial one option only)

_____My health care agent must follow these instructions.

**OR**

_____These instructions are only guidance. My health care agent shall have final say and may override any of my instructions. (Indicate any exceptions)

_____

_____

If I did not appoint a health care agent, these instructions shall be followed.

## Legal Protection

Pennsylvania law protects my health care agent and health care providers from any legal liability for their good faith actions in following my wishes as expressed in this form or in complying with my health care agent's direction. On behalf of myself, my executors and heirs, I further hold my health care agent and my health care providers harmless and indemnify them against any claim for their good faith actions in recognizing my health care agent's authority or in following my treatment instructions.

## Organ Donation (Initial one option only)

_____I consent to donate my organs and tissues at the time of my death for the purpose of transplant, medical study or education. (Insert any limitations you desire on donation of specific organs or tissues or uses for donation of organs and tissues.)

_____

_____

**OR**

_____I do not consent to donate my organs or tissues at the time of my death.

## Signature

Having carefully read this document, I have signed it this _____day of _____ , 20 ___,

revoking all previous health care powers of attorney and health care treatment instructions.

_____

(Sign full name here for health care power of attorney and health care treatment instructions.)

WITNESS: _____

WITNESS: _____

Two witnesses at least 18 years of age are required by Pennsylvania law and should witness your signature in each other's presence. A person who signs this document on behalf of and at the direction of a principal may not be a witness. (It is preferable if the witnesses are not your heirs, nor your creditors, nor employed by any of your health care providers.)

## Notarization (optional)

(Notarization of document is not required by Pennsylvania law, but if the document is both witnessed and notarized, it is more likely to be honored by the laws of some other states.)

On this _____ day of _____ , 20___ , before me personally appeared the aforesaid declarant and principal, to me known to be the person described in and who executed the foregoing instrument and acknowledged that he/she executed the same as his/her free act and deed.

In witness whereof, I have hereunto set my hand and affixed my official seal in the County of _____ , State of _____ the day and year first above written.

_____ _____

Notary Public My commission expires

# STEP 4

## DECIDE WHETHER YOU NEED ADDITIONAL EMERGENCY DOCUMENTS

This step is for people who want to provide instructions for receiving or not receiving emergency care.

Depending on your situation, you may wish to complete one or both of these forms:

- **OUT-OF-HOSPITAL DNR (DO NOT RESUSCITATE) FORM**
- **POLST (PHYSICIAN ORDERS FOR LIFE-SUSTAINING TREATMENT) FORM**

These are optional. They do not replace your advance directive. *Everyone needs an advance directive, but only some people need these emergency documents.*

### WHY HAVE AN OUT-OF-HOSPITAL DNR?

Imagine you have a medical emergency and someone calls 911. The emergency medical services (EMS) team arrives, intending to do everything they can to save your life. It's their job, and the law requires it.

Some people prefer not to have these emergency services. Generally, these are people who:

- Have a severe medical problem that cannot be improved and will likely cause death in the near future
- Don't want the EMS team to keep them alive, just want to be made as comfortable as possible

Having an Out-of-Hospital DNR tells the EMS team NOT to start resuscitation when you have cardiac and/or respiratory arrest. Many people with an Out-of-Hospital DNR also wear a medical bracelet or necklace that readily communicates their wishes to the EMS team.

Think about whether you want life-sustaining care. If not, and you meet certain medical criteria, the Out-of-Hospital DNR form may be right for you. If so, this form must be signed in advance by you and your doctor. Your surrogate decision maker can also sign for you.

This form is not binding. You can always change your mind or verbally communicate what you want to emergency responders.

By law the Out-of-Hospital DNR MUST be an original form obtained from the state by your doctor. Talk to your doctor if you are interested in learning more about it.

# STEP 4

## WHY HAVE A POLST?

A POLST may be useful if you have an end-stage or chronic medical condition, advanced frailty, or advanced age to further define your choices for end of life care. The POLST form lets you and your doctor create medical orders that direct treatment by EMS, hospitals, and other health care providers. For example, the POLST tells EMS and other care providers whether or not to:

- Resuscitate you
- Give you antibiotics
- Administer artificial nutrition or hydration

The POLST also allows you to decide what level of care you want, from full treatment with all life-sustaining efforts to only comforting care.

The POLST form must be printed on special paper. It must be signed by you (or your surrogate decision maker), and a doctor, nurse practitioner or physician assistant. Talk to your doctor if you are interested in learning more about it.

# STEP 5

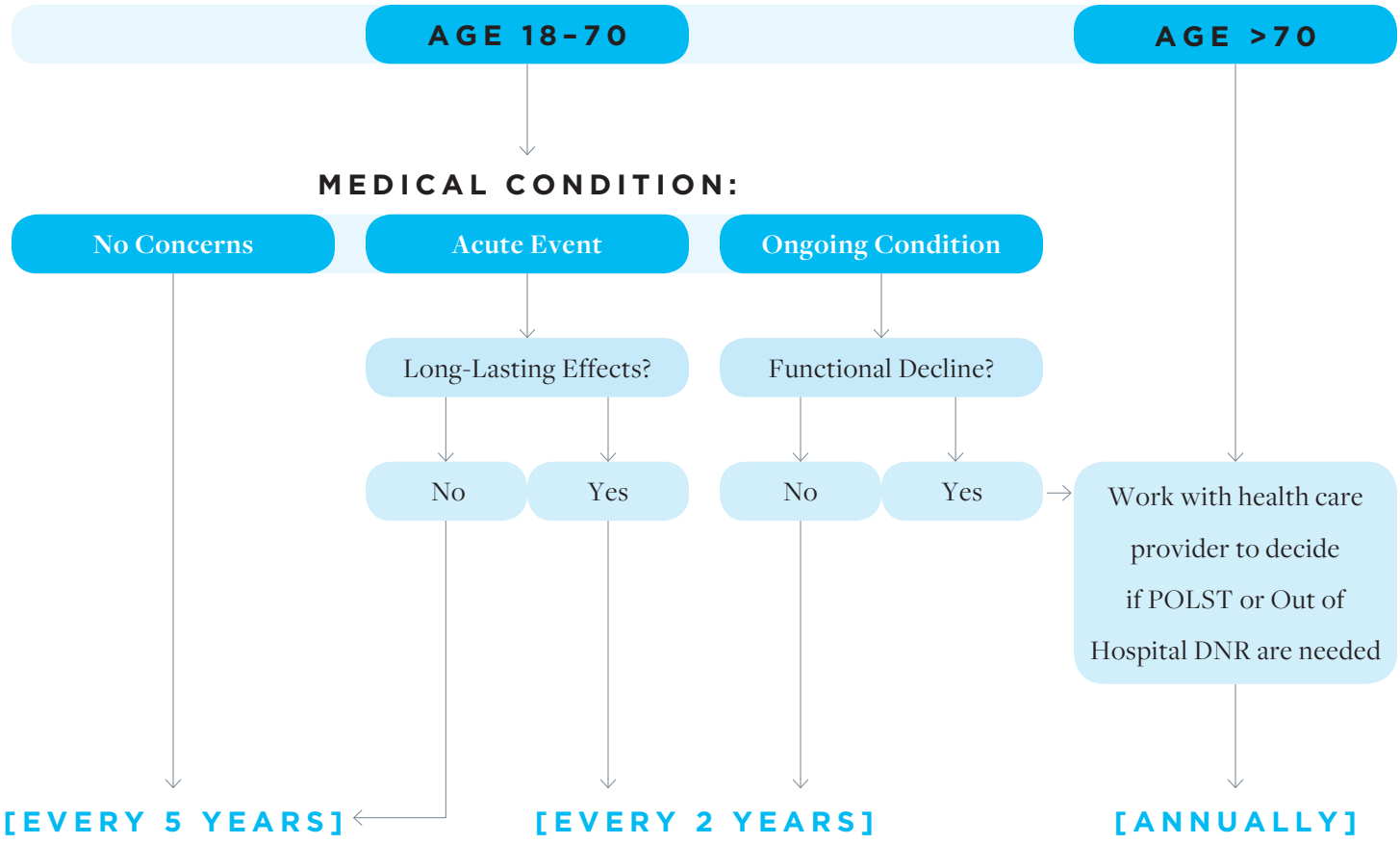
## REVIEW YOUR ADVANCE CARE PLAN REGULARLY

**ADVANCE CARE PLANNING IS AN ONGOING PROCESS.** Your views may change. What's important to you today may not be the same in the future. You may also decide to change your surrogate decision maker. That's why it's important to review your advance care plan on a regular basis.

Schedule time in your calendar. Make a point of periodically reviewing your advance care plan and other important documents.

### HOW OFTEN DO I NEED TO REVIEW MY PLAN?

As a general rule, if you are:



# STEP 6

## MAKE SURE YOUR DOCUMENTS CAN BE FOUND WHEN NEEDED

Take time now to make sure your wishes are known and your documents are readily available.

**THIS WILL HELP OTHERS FOLLOW YOUR WISHES.**

Share your advance care plan with anyone who might be involved in making decisions about your care if you are unable to do so. It's important to begin the conversation, even if it's uncomfortable at first.

**GIVE A COPY OF ALL DOCUMENTS TO YOUR PRIMARY CARE PROVIDER.**

### HERE ARE SOME SUGGESTIONS FOR KEEPING DOCUMENTS HANDY AND ORGANIZED:

- Place all documents in a plastic sleeve.
- Put the documents some place where they'll be easy to find quickly.
- Give your surrogate decision makers copies of all your advance care planning documents.
- If you have a POLST or Out-of-Hospital DNR, keep these on your refrigerator. This is where the emergency medical services team looks for them.
- Bring all documents to each hospitalization and whenever you're seeing new medical providers.
- If you change your documents, give the latest versions to your surrogate decision maker and doctors.

# RESOURCES

## WOULD YOU LIKE MORE HELP THINKING THIS THROUGH?

Search these agencies and organizations online **FOR MORE INFORMATION ABOUT ADVANCE CARE PLANNING.**

**National Healthcare Decisions Day (NHDD)**

**National Hospice and Palliative Care Organization**

**NIH National Institute on Aging**

**POLST (national)**

**POLST (Pennsylvania—UPMC)**

**The Cancer Conversation**

**The Conversation Project**

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