



our care wishes

**PATIENT WORKBOOK**

## **What is this packet?**

This packet is a resource that has been put together by Penn Medicine to help our patients make their wishes known. Our Care Wishes is a Penn Medicine created and run project, aimed at capturing our patients' care preferences so they can be followed.

This packet contains information about advance care planning. You can browse through this packet to help you as you are filling out your care plan or you can read it from start to finish before getting started.

### **When you are finished looking through this packet you will:**

- Know what an advance care plan (or wishes document) is
- Understand the steps to creating your own wishes document
- Have thought about your preferences and wishes
- Feel better prepared to create your wishes document
- Understand the legality of advance care plans and know how to make yours legal
- Know how to start conversations about these topics with people who matter to you including your family, friends, and doctors

## **What is an advance care plan? Why is it important?**

An advance care plan is a generic term used to describe a document that outlines your medical care preferences. Our Care Wishes calls this a "wishes document". The preferences you choose would be used to guide decisions about the care you receive if you became unable to communicate on your own behalf.

A blank wishes document is included in the same folder this packet came in. The purpose of this form is to let your doctors and loved ones know: who would make decisions for you if you became unable to speak for yourself, and what medical care you would and would not want.

## **What is an advance care plan? Why is it important? (cont)**

Your doctors and the rest of your care team at Penn Medicine want to provide you with the care you want whenever possible, and by filling out your wishes document, you will let us know what that is. Creating a document is the best way to ensure that you receive all types of care you do want, and none of the care you don't want.

### **What happens if I do not have an advance care plan or wishes document?**

If you do not have an advance care plan documented and available for care providers and loved ones, you may not receive care that you would want, or you might receive care that you do not want. Additionally, your loved ones could be faced with making difficult decisions and may be uncertain about what decisions to make regarding your care. When an individual does not have his or her wishes recorded, and becomes unable to speak for him or herself, a relative that person would not have wanted to make decisions for them may be the legal default in charge of their medical care. The patient may receive treatments that are not in alignment with what they wanted. Without a care plan, there would be nothing to protect against these situations.

### **When and how is an advance care plan used?**

Each state has its own policies on exactly when an advance care plan can be used. Similarly, different care providers can choose to use these documents in a variety of ways depending on the circumstances. Generally, they are used at a point when a patient has a terminal illness (they will not get better) and is no longer able to communicate (not able to talk, write, or express their opinions in any way), is not considered competent (unable to make decisions), or is permanently unconscious (they won't wake up).

### **Are there different kinds of advance care plans?**

Yes. There are many types of advance care plan documents. Each state may recommend a particular form, but it is your choice which form you use to document your care preferences. Our Care Wishes, the packet you have been provided, is the document preferred by Penn Medicine.

## ***Why is it important to have a wishes document?***

If a person becomes very sick and they are either permanently unconscious (won't wake up) or have an end-stage medical condition (won't get better), a wishes document can help to relieve their loved ones' fear and uncertainty. The document is most commonly used as a conversation guide between care providers and the patient's loved ones to determine which medical treatments best align with the patient's values and preferences. It can be difficult for family members if they are ever burdened with making decisions about what health care you should receive. The document you create provides guidance by telling them your wishes and what matters to you.

A wishes document can be useful in helping to resolve any conflict between loved ones who may have differing points of view on what health care you would want.

### **How does a wishes document help my family and care providers?**

Discussing your values and care preferences with loved ones and care providers can help them make the decisions that you would want if you were no longer able to communicate. Having your wishes documented and sharing it with others helps to make your wishes available if and when. It helps your care providers discuss treatment options with your loved ones and makes it much easier for everyone to confidently make decisions that they believe you would want.

## ***Why did I receive this information?***

Your care team has requested that you fill out a wishes document. We want to provide our patients with care that aligns with their wishes whenever possible. What matters to you matters to us, and we want to give you the opportunity to let us know what that is – and ensure that your wishes will be followed.

### **Who should complete?**

Everyone. It is never too early to discuss and document your care preferences.

## ***What types of decisions will this document ask me to make?***

### **There are 2 basic components of a wishes document:**

- **Living Will:** your personal values and what would be most important to you at the end of life
- **Durable Power of Attorney:** selecting your health care decision maker(s).

Our Care Wishes first asks you about quality of life preferences and if there are ways of living that you would find unacceptable. After that, you will specify which life sustaining treatments you do or do not want if you become very ill and will not get better. You will be asked about organ donation preferences. Another important component of the document is choosing your health care decision makers. These should be people you trust to make choices for you.

It is important to remember that all the choices you make on your wishes document are in the context of being very sick and unable to communicate. That is the only time this document would come into effect.

## About Health Care Decision Makers

### What is a “health care decision maker”? Why should I have one?

A health care decision maker can also be referred to as a durable power of attorney, health proxy, or surrogate. A health care decision maker is a person you name to make medical decisions for you if you become very sick and are unable to communicate yourself. Selecting one or two people to help make your medical decisions if you are no longer able to will help to ensure your wishes are followed. It is important to discuss your preferences with the decision makers you choose, so they know what you want.

Remember that your health care decision maker only becomes your decision maker IF and WHEN your document comes into effect. This is in the event that you become very sick and cannot speak for yourself. Your decision maker **DOES NOT** become your decision maker when you sign your wishes document.

### What if I don’t name a health care decision maker?

If you do not choose a health care decision maker, your doctors will ask your family or others close to you to serve as your decision maker. Who they ask, and in what order, will depend on the legal defaults in your state of residence. The person who becomes your decision maker will need to use any preferences recorded on your wishes document and work with your doctors to agree on a plan of treatment for you. That process can be difficult, confusing, and stressful for everyone involved.

### Who can I choose as a health care decision maker?

Your decision maker’s age must be at least 18 years old and they cannot be your doctor or someone who works at your hospital or clinic, unless they are related to you by blood, marriage, or adoption. You should choose people that you trust to follow your preferences and help make decisions regarding your care. They should be people who know you well and who would be available if they are ever needed to make medical decisions for you.

## **About Health Care Decision Makers (cont.)**

### **How many people can I select as a health care decision maker?**

It can be difficult to name one person as your decision maker. Although you can select more than one person, it is strongly recommended that you name a single primary decision maker and a single secondary decision maker. The more decision makers you select, the more difficult it can be for them to all agree on medical decisions.

NOTE: A secondary decision maker is only called upon if the primary decision maker is unreachable or does not accept the role of being your decision maker. The primary and secondary decision makers DO NOT “share” the decision making role.

## **What should I consider when thinking about my care preferences?**

The most important thing to consider is what you value in life for yourself and those around you. Though it is difficult, it is important to consider if there are things you must be able to do to feel your life is worth living, or if there are states of living that would be unacceptable to you.

Some people find it helpful to talk to their loved ones, health care providers, community leaders, or religious leaders whose perspectives they value. These individuals can help you talk through your thoughts and beliefs about end of life care. Take your time and remember the discussion is the most important part.

## **What are life sustaining treatments?**

Life sustaining treatments replace or support bodily functions that are no longer working. When people have treatable conditions, life sustaining treatments are used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. At times, the body never regains the ability to function without life support or life-sustaining treatment.

### **Some common examples of life-sustaining treatments include:**

- Intervention if your heart stops, including Cardiopulmonary Resuscitation (CPR).
- Intubation, the placement of a flexible plastic tube into the trachea (windpipe) to maintain an open airway, so you can breathe.
- Mechanical Ventilator, machine assisted breathing.
- Dialysis, the clinical purification of blood by a machine that substitutes for the normal function of the kidneys.
- Antibiotics, to treat infections.
- Artificial nutrition and hydration, liquid food or water that is medically supplied by a tube into your nose, or directly into your stomach, intestine, or veins.

## **How do I make my wishes document legal? Do I have to?**

In order to make your wishes document a legal document, you and at least 2 witnesses must sign it. Witnesses cannot be your care providers, or the health care decision makers you have named on your directive. Alternatively, you can have your wishes document notarized.

The main benefit of making your wishes document legal (having it signed with witnesses or notarized) is in resolving conflict among your loved ones regarding medical decisions on your behalf. This situation is not very common, and it is up to you to decide whether making your document legal is important given your circumstances.



## ***How do I make my wishes document legal? Do I have to? (cont.)***

### **Is my wishes document valid in any state, at any health care facility?**

While each state usually has a specific advance care plan form and guidelines on how they are followed, the differences from state to state are minimal. While specifics may be slightly different from state to state, it is important to remember that any documentation of your preferences is better than none. Your document will be extremely useful in helping to guide decision making at any health care facility in any state.

### **How do I make sure my advance directive is available?**

The most current, and available, document is the one that will be used by your care providers. Your nurse or provider will help get your document into your medical record so it is accessible to your care team. If you want to update your preferences, you can ask your provider to bring you another Our Care Wishes document. When you sign a document, it invalidates and overrides all past documents, including those made through any other service or platform.

## ***How do I start a conversation about my preferences?***

Any type of conversation that involves thinking about end of life can be difficult. It is important to remember that this is not a conversation about death but about how you want to live. It is an opportunity to discuss what is important to you with the people you care about. Talking about your preferences can greatly reduce the burden on your loved ones if they ever have to make health care decisions for you.

### **Who should I share my wishes document with?**

You should share your document with your health care decision maker(s), loved ones who would want to make sure your wishes were followed, and care providers who can also help answer any questions you may have. Remember to follow up with a conversation with the people you share your document with. A little conversation goes a long way in terms of clarifying any questions they may have about the preferences you have recorded.

## About me

NAME  
FIRST

LAST

DATE OF BIRTH

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## Decision Maker(s)

### Primary Decision Maker

PRIMARY DECISION MAKER'S NAME  
FIRST

LAST

RELATIONSHIP  
TO ME

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ADDRESS  
STREET

/ CITY

/ STATE

/ ZIP

---

CONTACT INFO  
EMAIL

PHONE

---

### Secondary Decision Maker

SECONDARY DECISION MAKER'S NAME  
FIRST

LAST

RELATIONSHIP  
TO ME

---

ADDRESS  
STREET

/ CITY

/ STATE

/ ZIP

---

CONTACT INFO  
EMAIL

PHONE

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- OR -

*I choose NOT to name a health care decision maker.* (CHECK BOX IF APPLIES)

## My Quality of Life Preferences

The following prompts are related to your quality of life. Quality of life is about the things you are able to do or not do, and how much those things matter to you. It is important to consider what matters most to you and makes your life worth living. Some things matter more to certain people, and others matter less. Your document should express what matters most to you.

	<i>This is worse than dying comfortably</i>	<i>This is neither better nor worse than dying comfortably</i>	<i>This is better than dying comfortably</i>
I am confused all the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I rely on a feeding tube to live	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I rely on a breathing machine to live	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I cannot control my bladder or bowels	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I need care all the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I cannot live outside of a hospital or medical facility	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have to stay at home all day	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am in moderate pain all the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I cannot get out of bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I am wheelchair bound	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

*What else do you want your doctors to know about your quality of life goals?*

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## My Medical Treatment Preferences

Life sustaining treatments replace or support bodily functions that are no longer working. When people have treatable conditions, life support is used temporarily until the illness or disease can be stabilized and the body can resume normal functioning. However, when a person becomes very sick, the body never regains the ability to function without life support or life-sustaining treatment. It is important to consider what treatments you would want your doctors to use long-term if you were not going to get better.

*Now imagine that you are very sick. Your doctors tell you that you will not get better, and you may not have long to live. Overall, what do you want to be the goal of your medical care?*



I want treatments to focus on comfort and my quality of life.



I want to focus on prolonging my life, but I only want to try life support treatments for a short time. If my doctors decide that the treatments are not helping, I want them stopped.



I want all treatments to prolong my life.



I only want some treatments to prolong my life. *(Select a list of treatments you want)*



### **Cardiac resuscitation**

Cardiac resuscitation means pressing very hard on your chest and giving you shocks if your heart stops.



### **Breathing machine**

A breathing machine, or ventilator, helps you breath. You cannot talk while you are connected to the ventilator.



### **Dialysis**

Dialysis uses a special machine to clear your blood when your kidneys do not work.



### **Surgery**



### **Chemotherapy for cancer**



### **Artificial nutrition**

Artificial nutrition is given through a feeding tube placed in your mouth, nose, or stomach. Sometimes nutrition is also given directly into the blood through a tube in a vein (IV).



### **Hydration**

Fluid is given directly to the blood through a tube in a vein (IV).



### **Antibiotics**

Antibiotics are given to treat infections. Sometimes they are taken as a pill. Other times they are given through a tube in a vein (IV).



### **Blood transfusions**

Blood is given through a tube in a vein (IV).

## Organ Donation

Donating your organs after you die can help save lives. A single person who chooses to donate organs after death can help save as many as 10 people. It's a way to give back and support others.

Everyone can sign up for organ donation and most people choose this option, regardless of age or illness. Even people with serious medical illnesses can donate their organs.

Choosing to be an organ donor doesn't affect your health care when you are alive. Our Care Wishes recommends choosing to donate your organs so you can help save or improve other people's lives.

*Select one that applies:*

*After I die, I would like to donate any organs that can help someone else*

- OR -

*After I die, I will donate all my organs **EXCEPT:***  
(LIST ORGANS YOU CHOOSE NOT TO DONATE)

- OR -  *I choose **NOT** to donate any of my organs.* (CHECK BOX IF APPLIES)

*On behalf of myself, my executors and heirs, I hold my health care decision maker and my health care providers harmless and indemnify them against any claim for their good faith actions in recognizing my health care decision maker's authority or in following my treatment instructions.*

*I, having carefully read this document, have signed it this \_\_\_\_\_ DAY \_\_\_\_\_ MONTH AND YEAR \_\_\_\_\_, revoking all previous health care powers of attorney and health care treatment instructions.*

YOUR SIGNATURE  
(SIGN HERE)

\_\_\_\_\_

YOUR NAME  
(PRINT HERE)

\_\_\_\_\_

**WITNESSES**

WITNESSES MUST BE AT LEAST 18 YEARS OF AGE, KNOW YOU, AND SEE YOU SIGN THIS FORM. WITNESSES CANNOT BE YOUR HEALTH CARE DECISION MAKER OR HEALTH CARE PROVIDER.

*By signing, I promise that \_\_\_\_\_ APPLICANT'S FULL NAME \_\_\_\_\_ signed this form while I watched. He/she was thinking clearly and was not forced to sign it.*

WITNESS #1  
SIGNATURE

\_\_\_\_\_

FIRST NAME:

LAST NAME

\_\_\_\_\_

\_\_\_\_\_

CITY

STATE

ZIP CODE

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

WITNESS #2  
SIGNATURE

\_\_\_\_\_

FIRST NAME:

LAST NAME

\_\_\_\_\_

\_\_\_\_\_

CITY

STATE

ZIP CODE

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_