Project Talk

Conversations that Matter

Advance Care Planning Workbook with Advance Directive

Name_____ Date _____

This booklet was created for use with the Project Talk Trial. Portions of the booklet were adapted with permission by Vital Decisions.

TAKE THE NEXT STEPS

Thank you for participating in the Project Talk Trial.

Congratulations! You have taken the first and hardest step to prepare for medical decision-making! We hope today's conversation activity helped you clarify your values and wishes for medical care, and that doing this motivates you to complete an advance directive. But you're not done yet.

Here are more steps you can take:

- ☑ **Think** about the kind of medical care you would want to receive if you were very sick.
- ○ **Choose** a person who you trust to make medical decisions for you if you can't make decisions for yourself. This person is your **spokesperson (often called a healthcare proxy or agent).**
- ○ **Talk** with your chosen decision-maker about your wishes.
- ○ **Write** your wishes on your advance directive forms.
- ○ **Notarize** your advance directive forms **using our project notary free of charge**! While not all states require notarization, it is helpful to formalize your document, and our event host can help you contact a notary.
- ○ **Return** the Project Talk tear-off page to show us that you completed the process. This is an important part of our research! We do NOT need to see your entire advance directive – only the tear-off page (carbon copy).
- ○ **Share** your advance directive with your healthcare providers and loved ones.
- ○ **Review** your advance directive with your healthcare providers and medical decision-makers from time to time. You can change your mind about the kind of care you want at any time.

WHAT IF I ALREADY HAVE AN ADVANCE DIRECTIVE?

Even if you have already completed an advance directive before being involved in this project, we still need to record this for our research purposes. **Please follow the steps below if you have an existing advance directive.**

I **DO NOT** want to change my existing advance directive:

- **Review** your existing advance directive and make sure you still agree with what it says
- **Re-sign and re-date** the signature page to show that you have recently reviewed it and still agree with what it says
- **Provide** updated copies of your re-signed document to your loved ones and clinicians to show that you recently reviewed it
- **Show** your advance directive to your Project Talk notary public, who will confirm they reviewed your signature

-OR-

Send a copy of your Advance Directive Signature page to Project Talk for our research records.

I **DO** want to change my advance directive:

- **Complete** this workbook which will replace your old advance directive
- **Destroy** your old document (or mark it as void and then sign and date it)
- **Tell** your family and clinicians to destroy the old copies of your advance directive
- **Provide** copies of your new advance directive to your family and clinicians
- **Show** your advance directive to your Project Talk notary, who will confirm they reviewed your signature
- **Send** a copy of your Advance Directive Signature page to Project Talk for our research records.

3 Ways to Send Us a Copy of Your Advance Directive Signature

1. **Send a copy to:** your event host
2. **Email a copy to:** ProjectTalk@pennstatehealth.psu.edu
3. **Mail a copy in the postage-paid, self-addressed envelope to:**
   Penn State College of Medicine
   Attn: Project Talk, MC SB37
   50 HMC Long Lane, SSB Building, Suite 205, Hershey, PA 17033

TOP 10 FAQS ABOUT ADVANCE CARE PLANNING

1 What is Advance Care Planning?

If you're like most people, you may have strong feelings about medical treatments you want or don't want to receive. But what happens if you cannot speak for yourself? Communicate your values and beliefs before illness or injury strikes, so that others can know what matters most to you.

Advance care planning is the process of preparing for future medical care in the event you are unable to make your own decisions. It involves clarifying your values and goals, discussing your medical wishes with loved ones and healthcare providers, and making sure that your preferences are known—which may involve written documents, powers of attorney, and medical orders.

Advance Directives are written instructions that document your wishes regarding medical treatment. They contain information about the medical care you want or don't want, as well as other information that explains your wishes. They may also indicate who you would want to make decisions on your behalf if you were unable to do so yourself.

Living Wills are a type of advance directive (a legal form) that is used when one faces a life-threatening condition and is unable to communicate their desires for medical treatment. The living will specifies **WHAT** kinds of treatments you would want (or not want) to receive.

Health Care Power of Attorney (HCPOA) is a type of advance directive (a legal form) that identifies **WHO** you wish to speak on your behalf regarding your medical wishes when you are unable to do so yourself. The HCPOA is often a part of other documents called Advance Directives or Living Wills. Your HCPOA could be one or more people, however, it is best to name one person as the final **spokesperson** (often called your healthcare proxy or healthcare agent).

2 Who should I entrust to be my spokesperson?

Before you name a spokesperson, you may have some questions about how to choose the right person. For some people, choosing a spokesperson is simple. For others, it is difficult to decide which family member or friend they would want to speak for them.

Your spokesperson should be someone whom…

- you trust
- is willing to speak on your behalf
- knows your values and preferences
- can separate their feelings from yours
- is willing to abide by your wishes
- will be available when needed
- can make good decisions and stick by them

3 What happens if I don't choose a spokesperson?

If you don't choose a spokesperson, conflicts may arise about who should speak for you. With or without your input, decisions still need to be made, and someone WILL be chosen—either on a case-by-case basis or according to a pre-determined sequence (such as one's spouse, then one's son or daughter, and so on).

4 What does a spokesperson do?

A spokesperson speaks for you when you cannot. This person has the responsibility to make decisions on your behalf about medical treatments. Their job is to communicate with your doctors, to ask questions, and to represent your views as accurately as possible.

5 How do I name a spokesperson?

It's a good idea to first speak with the person about your goals, values, and preferences. Be sure that this person understands your wishes and is willing to serve as a spokesperson for you. Simply complete the information in this booklet, sign it and ask two witnesses to sign. Rules on who can witness the form differ from state to state, and some states require notarization. Ask your event host for information about your state.

6 How can I cancel or change my named spokesperson or wishes?

If you change your mind, you can cancel or change your named spokesperson by notifying him or her verbally or in writing.

- If you want to change the document, you must complete a new one
- Then, write "Revoke" in large letters across the name of each spokesperson whose authority you want to cancel on the original and then sign and date it again.
- To make sure there is no misunderstanding, provide the new document to anyone who has a copy of the original, including your healthcare provider.

7 Do doctors have to follow the decisions of my spokesperson?

As long as the doctor thinks that your spokesperson is accurately representing your wishes, he or she is legally and morally obligated to regard your spokesperson's decisions as yours. Like all medical decisions, a doctors professional judgement plays a role in what will be done, however if the spokesperson's request is medically reasonable the doctors are supposed to follow it.

8 When does the Health Care Power of Attorney take effect?

After being signed and dated in the presence of two witnesses, the HCPOA takes effect only during the time you are unable to make your own medical decisions.

9 Who can witness the Health Care Power of Attorney document?

This document must be witnessed by 2 adults, 18 years of age or older, preferably a member of your family or a friend.

A witness **cannot be** (1) you, (2) your designated spokesperson, (3) an individual signing the document on your behalf (if you are physically unable to sign) or (4) a health care provider who is involved in your care.

10 My form is signed and witnessed. Now what should I do?

- Keep the original document in a secure but accessible place.
- Give a copy to your medical team in the clinics and hospitals where you receive care.
- Give copies to your spokesperson and alternative spokesperson, family, and anyone who might be involved in your health care.
- Talk to your health care team or consult an attorney for your legal options, if you wish to express your preferences in greater detail.
- Send a copy of your Advance Directive Signature page to Project Talk by **(1) giving a photo or copy to your event host, (2) showing it to the Project Talk notary public,(3) emailing it to ProjectTalk@pennstatehealth.psu.edu or (4) mailing it to Project Talk in the postage-paid, self-addressed envelope provided.**

MY ADVANCE DIRECTIVE

Advance Care Plan

Sometimes it happens slowly, sometimes suddenly. But a time may come when I am unable to speak for myself.

When that time comes, decisions still need to be made by those closest to me. It is important that they know the kind of medical treatment I would want—and not want— to receive.

The following pages clarify my wishes for medical treatment. It is also a starting point for conversations with my doctors, my spokesperson, and loved ones.

These written instructions apply only if I am unable to speak for myself.

My contact information

Today's Date: / /

Full Name:

Date of Birth: / /

Phone: ( )

Street Address:

Apt/Unit:

City:

State:

Zip Code:

SECTION 1

Living with physical limitations

It's important that my doctor and loved ones know how I would feel about living with specific physical, mental, or social limitations—and how acceptable I would find my life if faced with each of the following circumstances. **There are no right or wrong answers. Select the response that best expresses how you feel.**

1 If I were confined to bed all the time, I would consider my quality of life to be: (Check *only* one.)

- ◯ Acceptable
- ◯ Acceptable, but difficult
- ◯ Not worth living

---

2 If I could not walk but could get around in a wheelchair, I would consider my quality of life to be: (Check *only* one.)

- ◯ Acceptable
- ◯ Acceptable, but difficult
- ◯ Not worth living

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3 If I had severe pain most of the time, I would consider my quality of life to be: (Check *only* one.)

- ◯ Acceptable
- ◯ Acceptable, but difficult
- ◯ Not worth living

SECTION 1

Living with physical liminations (continued)

4 **If I had discomfort and pain most of the time, such as nausea, diarrhea, or shortness of breath, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

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5 **If I could not control my bladder and bowels, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

Additional Notes or Thoughts

SECTION 2

Living with mental limitations

6 **If I could no longer make my own decisions, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

---

7 **If I could not think clearly and was confused most of the time, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

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8 **If I could not communicate in a way that could be understood by others, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

SECTION 3

Living with social limitations

9 **If I had to live permanently in a nursing home, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

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10 **If I could not have meaningful relationships with family or friends, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

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11 **If I were so debilitated that my care caused a severe burden to my family, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

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12 **If I were so debilitated that the cost of my care caused a severe financial burden to my family, I would consider my quality of life to be: (Check *only* one.)**

- ○ Acceptable
- ○ Acceptable, but difficult
- ○ Not worth living

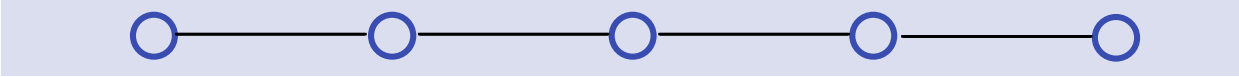
SECTION 4

What else is important to me?

Medical decisions can be complicated, and often involve trade-offs. My preferences for medical care are based on what matters most to me. The following statements should provide helpful and detailed guidance for those who may make decisions on my behalf if I am unable to speak for myself.

13 Pain vs. Alertness

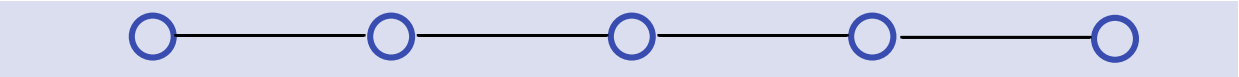
When choosing between being free from pain and being alert, I would choose: **(Check *one* circle.)**



Freedom from pain — **Being alert**

14 Suffering vs. Living Longer

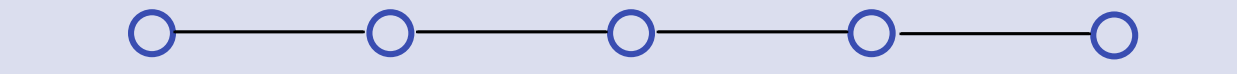
When choosing between avoiding suffering and living longer, I would choose: **(Check *one* circle.)**



Avoid suffering — **Living longer**

15 Death vs. Time for Family Members

When choosing between avoiding a prolonged death and allowing time for family members to see me, I would choose: **(Check *one* circle.)**



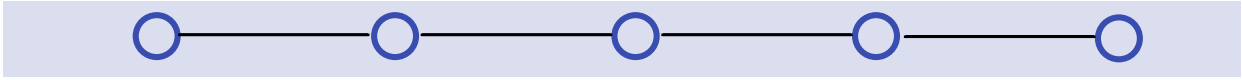
Avoid a prolonged death — **Allowing time for my family to see me**

SECTION 4

What else is important to me? (continued)

16 Dying at Home vs. Access to Hospital Services

When choosing between dying at home and having access to hospital services, I would choose: **(Check *one* circle.)**



Dying at home — **Access to hospital services**

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17 Independence vs. Help from Others

When evaluating the trade-offs between caring for myself versus accepting help from others, I would choose to: **(Check *one* circle.)**

Maintain independence — **Accept help from others**

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18 Costs vs. Treatment

When choosing between being mindful of costs and pursuing all possible treatment options, I would choose: **(Check *one* circle.)**

Be mindful of costs — **Pursuing all options**

SECTION 5

If I face a medical crisis

19 **If others must make medical decisions for me in a medical crisis, they should know my general wishes. Here's the best guidance I can give. If faced with a medical crisis, I would want: (Check one circle.)**

○ Comfort Measures Only/Allow Natural Death

I want to be comfortable and not in pain, even if this shortens my life. I want to avoid going to the hospital unless it is necessary to relieve my pain and suffering. I don't want aggressive, high tech measures to prolong my life.

○ Selective Care

I want treatment to relieve symptoms and prolong life, but only if it is likely to preserve what I consider to be an acceptable quality of life. Treatment should be stopped when it does not accomplish this goal, and would leave me with an unacceptable quality of life.

○ No Limits

I want to be treated in any possible way to prolong my life, even if the chance of success is slim, and my quality of life would be diminished.

Additional Notes or Thoughts

_____

_____

_____

_____

_____

_____

_____

SECTION 6

Additional wishes

20 **When I think about organ and tissue donation: (Check *one* circle.)**

- ○ I would want to donate any organs or tissues
- ○ I would want to donate organs or tissues, but with exceptions
- ○ I would NOT want to donate any organs or tissues

Any **exceptions** for organ and tissue donations are detailed here (for example: internal organs, eyes, etc.):

_____

_____

21 **(OPTIONAL) Many people have values, spiritual beliefs, or religious traditions that influence the medical decisions they make. Here is additional guidance about what's important to me, and that I want others to know:**

_____

_____

_____

My joys

I want my doctor to know more about what gives me satisfaction and what causes me concern. This may include things I want to be able to do, like having an active lifestyle, or making time for family. It may also include concerns like losing independence, being unable to care for a loved one, or burdening others with high costs of medical care.

22 **Things in life that give me joy and keep me going:**

_____

_____

_____

SECTION 7

My preferred spokesperson

A spokesperson will make decisions for you if you are unable to communicate your wishes. By designating a spokesperson, you choose who will speak on your behalf. It's a good idea to first speak with the person about your goals, values, and preferences. Be sure that this person understands your wishes, and is willing to serve as a spokesperson for you.

Spokesperson's Full Name:		
Relationship to Me:		
Street Address:		**Apt/Unit:**
City:	**State:**	**ZIP Code:**
Home Phone: ( )	**Mobile Phone: ( )**	
Other Phone: ( )		

My substitute spokesperson

If the first person I named is unable, unwilling, or unavailable to act as my spokesperson, I name the following individual to be my substitute spokesperson:

Spokesperson's Full Name:		
Relationship to Me:		
Street Address:		**Apt/Unit:**
City:	**State:**	**ZIP Code:**
Home Phone: ( )	**Mobile Phone: ( )**	
Other Phone: ( )		

SECTION 7 (CONTINUED)

Other individuals I would like involved

I would like my spokesperson (or substitute spokesperson) to talk with the following individuals before making healthcare decisions for me. These individuals may provide advice and guidance, but will NOT have veto power over my spokesperson's decisions.

Full Name:	
Relationship:	**Phone: ( )**

Full Name:	
Relationship:	**Phone: ( )**

Full Name	
Relationship:	**Phone: ( )**

Individuals I would NOT like involved

I would **NOT** like the following individuals involved in decision-making on my behalf.

Name:	**Relationship:**
Name:	**Relationship:**

SECTION 7 (CONTINUED)

When these instructions should apply

What would you want done if you are unable to speak for yourself, and your spokesperson's judgments conflict with the instructions expressed in your written instructions?

In this situation, I would want:

- ○ My spokesperson's judgments to override my written instructions
- ○ My written instructions to override my spokesperson's judgments

Additional guidance for my spokesperson

My spokesperson is authorized to make all healthcare decisions for me permitted by law, including decisions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of healthcare to keep me alive, unless I specify any limitations here:

Specify below any *limitations* you wish to place on your spokesperson.

NEXT STEPS

Discuss your Advance Directive with others.

Just filling out this document is not enough to ensure that your wishes will be followed. If they are locked in a safety deposit box or hidden away in a file cabinet, they are less likely to be of use.

Share this document with your spokesperson (also called your healthcare proxy or agent) so they know your goals, values, and preferences, and will be prepared when the time comes. Be sure this person understands your wishes and is willing to serve as your spokesperson.

Finally, for advance care planning to be effective, you need to **discuss** your wishes and share your documents with family members, friends, healthcare providers, and others so they can help make sure your wishes are followed.

What if you change your mind?

You can change your written instructions at any time, and it's a good idea to revisit them every couple of years or if your medical condition changes. **Please know that these written instructions apply only if you are not able to speak for yourself.**

Return to Project Talk

Please be sure to return the carbon copy of the next page of this booklet,
Your Advance Directive Signature Page**, to your host *or*** return it to us
by email at ProjectTalk@pennstatehealth.psu.edu *or* by
using the postage-paid, self-addressed envelope provided.

YOUR ADVANCE DIRECTIVE SIGNATURE PAGE

Make it official.

You have completed your Advance Directive, and made an important investment in living—on your terms.

- If unable to sign, you may specifically direct another individual to sign and date on your behalf.

To make this a LEGALLY valid document:

- Review carefully and feel free to edit it as needed.
- Sign the signature page in the presence of two witnesses
- Some states require that your advance directive be signed by a notary. The host of your event will help you connect with a notary public (at no charge) if you would like.

MY SIGNATURE

I, _____ **(Please print name clearly)**

ask that my family, loved ones, doctors, and other healthcare providers follow my wishes as communicated by my spokesperson (healthcare proxy or agent) or as otherwise expressed in my Advance Directive.

_____ _____

Signature **Today's Date**

WITNESSES

_____

Signature of Witness Date/Time

_____

Signature of Witness Date/Time

Return to Project Talk

Please be sure to **return the carbon copy of this page to your host** *or* return it to us **by email at ProjectTalk@pennstatehealth.psu.edu** *or* **by using the postage-paid, self-addressed envelope provided.**

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(back of Advance Directive
Signature Page)

NOTARIZATION

Please check you state law for whether or not your Advance Directive must be notarized by a notary public.

State of _____ County of _____

On this _____ day of _____, 20_____ the said _____

came before me personally and, under oath, stated that he/she is the person described in the above Advance Directive and he/she signed the above document in my presence; and he/she appears to be of sound mind and under no duress, fraud, or undue influence, and I:

- am not a healthcare provider;
- am not designated as the individual's spokesperson (healthcare proxy or agent) or alternate;
- am not related to the individual by blood, marriage, or adoption;
- am not entitled to any portion of the individual's estate, either through his/her will or codicil thereto, or by operation of law;
- do not have a claim against the individual's estate;
- am not directly financially responsible for the individual's healthcare;
- am not an employee, owner, or operator of a healthcare facility;
- am not an employee, owner, or operator of a residential care facility for the elderly; or
- am not an employee of the individual's life insurance provider or health insurance provider.

Notary Public _____ My Commission Expires _____

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Additional Notes or Thoughts

Project Talk

Conversations that Matter

Project Talk Trial

HFA HOSPICE FOUNDATION OF AMERICA

PennState College of Medicine

College of Communication and Information
Department of Communication

Project Talk

Penn State College of Medicine
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