Caring Connections, a program of the National Hospice and Palliative Care Organization (NHPCO), is a national consumer engagement initiative to improve care at the end of life, supported by a grant from The Robert Wood Johnson Foundation.

Caring Connections tracks and monitors all state and federal legislation and significant court cases related to end-of-life care to ensure that our advance directives are up to date.

It's About How You LIVE

It's About How You LIVE is a national community engagement campaign encouraging individuals to make informed decisions about end-of-life care and services. The campaign encourages people to:

- **L**earn about options for end-of-life services and care
- **I**mplement plans to ensure wishes are honored
- **V**oice decisions to family, friends and healthcare providers
- **E**ngage in personal or community efforts to improve end-of-life care

Please call the HelpLine at 800/658-8898 to learn more about the LIVE campaign, obtain free resources, or join the effort to improve community, state and national end-of-life care.

If you would like to make a contribution to help support our work, please visit [www.nationalhospicefoundation.org/donate](http://www.nationalhospicefoundation.org/donate). Contributions to national hospice programs can also be made through the Combined Health Charities or the Combined Federal Campaign by choosing #11241.

Support for this program is provided by a grant from The Robert Wood Johnson Foundation, Princeton, New Jersey.
Your Advance Care Planning Packet

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Using these materials

BEFORE YOU BEGIN
1. Check to be sure that you have the materials for each state in which you may receive healthcare.

2. These materials include:
   • Instructions for preparing your advance directive.
   • Your state-specific advance directive forms, which are the pages with the gray instruction bar on the left side.

PREPARING TO COMPLETE YOUR ADVANCE DIRECTIVE
3. Read the HIPAA Privacy Rule Summary on page 4.

4. Read all the instructions, on pages 7 through 8, as they will give you specific information about the requirements in your state.

5. Refer to the Glossary located in Appendix A if any of the terms are unclear.

ACTION STEPS
6. You may want to photocopy these forms before you start so you will have a clean copy if you need to start over.

7. When you begin to fill out the forms, refer to the gray instruction bars - they will guide you through the process.

8. Talk with your family, friends, and physicians about your advance directive. Be sure the person you appoint to make decisions on your behalf understands your wishes.

9. Once the form is completed and signed, photocopy the form and give it to the person you have appointed to make decisions on your behalf, your family, friends, healthcare providers and/or faith leaders so that the form is available in the event of an emergency.

If you have questions or need guidance in preparing your advance directive or about what you should do with it after you have completed it, please refer to the state-specific contacts for Legal & End-of-Life Care Resources Pertaining to Healthcare Advance Directives, located in Appendix B.
Summary of the HIPAA Privacy Rule

HIPAA is a federal law that gives you rights over your health information and sets rules and limits on who can look at and receive your health information.

Your Rights

You have the right to:
- Ask to see and get a copy of your health records.
- Have corrections added to your health information.
- Receive a notice that tells you how your health information may be used and shared.
- Decide if you want to give your permission before your health information can be used or shared for certain purposes, such as marketing.
- Get a report on when and why your health information was shared for certain purposes.
- If you believe your rights are being denied or your health information isn't being protected, you can:
  - File a complaint with your provider or health insurer, or
  - File a complaint with the U.S. Government.

You also have the right to ask your provider or health insurer questions about your rights. You also can learn more about your rights, including how to file a complaint from the Web site at www.hhs.gov/ocr/hipaa/ or by calling 1-866-627-7748.

Who Must Follow this Law?

- Doctors, nurses, pharmacies, hospitals, clinics, nursing homes, and many other healthcare providers.
- Health insurance companies, HMOs, most employer group health plans.
- Certain government programs that pay for healthcare, such as Medicare and Medicaid.

What Information is Protected?

- Information your doctors, nurses, and other healthcare providers put in your medical record.
- Conversations your doctor has had about your care or treatment with nurses and other healthcare professionals.
- Information about you in your health insurer's computer system.
- Billing information about you from your clinic/healthcare provider.
- Most other health information about you, held by those who must follow this law.
Summary of the HIPAA Privacy Rule (continued)

Providers and health insurers who are required to follow this law must keep your information private by:

- Teaching the people who work for them how your information may and may not be used and shared,
- Taking appropriate and reasonable steps to keep your health information secure.

To make sure that your information is protected in a way that does not interfere with your healthcare, your information can be used and shared:

- For your treatment and care coordination,
- To pay doctors and hospitals for your healthcare,
- With your family, relatives, friends or others you identify who are involved with your healthcare or your healthcare bills, unless you object,
- To protect the public's health, such as reporting when the flu is in your area, or
- To make required reports to the police, such as reporting gunshot wounds.

Your health information cannot be used or shared without your written permission unless this law allows it. For example, without your authorization, your provider generally cannot:

- Give your information to your employer.
- Use or share your information for marketing or advertising purposes, or
- Share private notes about your mental health counseling sessions.
INTRODUCTION TO YOUR PENNSYLVANIA ADVANCE DIRECTIVE

This packet contains a legal document that protects your right to refuse medical treatment you do not want, or to request treatment you do want, in the event you lose the ability to make decisions yourself.

The Pennsylvania Directive is your state’s living will. It lets you state your wishes about medical care in the event that you develop a terminal condition or enter a state of permanent unconsciousness and can no longer make your own medical decisions. The Living Will becomes effective when your doctor receives a copy of it and determines that you are incompetent and in an end-state medical condition or a state of permanent unconsciousness. In your Directive you can name another person, called a healthcare agent, to make decisions about your medical care—including decisions about life support—when you can no longer speak for yourself.

Note: This document will be legally binding only if the person completing it is an individual of sound mind who is 18 years or older, or if a minor, is married, emancipated or a high school graduate.
COMPLETING YOUR PENNSYLVANIA DECLARATION

How do I make my Pennsylvania Directive legal?

In order to make your Directive legally binding, you must date and sign it, or direct another to sign it, in the presence of two witnesses who must also sign the document to show that you knowingly and voluntarily signed the document. Both of your witnesses must be 18 years or older and, if you are unable to sign your Directive, neither witness can be the person who signed the Directive on your behalf.

*Note: You do not need to notarize your Pennsylvania Directive.*

Whom should I appoint as my healthcare agent?

Your healthcare agent is the person you appoint to make decisions about your medical care if you become unable to make those decisions yourself. Your healthcare agent should be an adult, and can be a family member or a close friend whom you trust to make serious decisions. The person you name as your healthcare agent should clearly understand your wishes and be willing to accept the responsibility of making medical decisions for you. (A healthcare agent may also be called a “surrogate,” “attorney-in-fact,” or “proxy.”)

You can appoint a second or third person as your alternate healthcare agent. The alternate will step in if the first person you name as surrogate is unable, unwilling or unavailable to act for you.

Can I add personal instructions to my Directive?

Yes. You can add personal instructions in the part of the document called “Other directions.”

If you have appointed a healthcare agent, it is a good idea to write a statement such as, “Any questions about how to interpret or when to apply my Directive are to be decided by my agent.”
COMPLETING YOUR PENNSYLVANIA DIRECTIVE (CONTINUED)

What if I change my mind?

You may revoke your Pennsylvania Directive at any time and in any manner. Your revocation becomes effective when you, or a witness to your revocation, notify your doctor or other healthcare provider. Once your doctor is notified, he or she must then make the revocation a part of your medical record.

What other important facts should I know?

A pregnant patient’s Pennsylvania Directive will not be honored, due to restrictions in the state law, unless life-sustaining treatment will not permit the development and live birth of the unborn child, will be physically harmful to the pregnant woman, or will cause her pain that cannot be alleviated by medication.

Your Directive goes into effect when a copy is provided to your attending physician and your attending physician determines that a healthcare provider has documented that despite being provided appropriate medical information, communication supports and technical assistance, you are unable to understand the potential material benefits, risks and alternatives involved in a specific proposed healthcare decision, you are unable to make that healthcare decision on your own behalf, and you are unable to communicate that healthcare decision to any other person; and you are determined to be in an end-stage medical condition or permanently unconscious. Your attending physician must promptly certify in writing that you have an end-stage medical condition or are permanently unconscious.
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 (OPTIONAL)

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.):

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

OR

**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 (Optional)

Under Pennsylvania law, you may make a gift of all or part of your body to a bank or storage facility or a hospital, physician or medical or dental school for transplantation, therapy, medical or dental evaluation or research or for the advancement of medical or dental science. In the space below you may make a gift yourself or state that you do not want to make a gift. An individual may revoke or amend an anatomical gift by: (1) destruction, cancellation or mutilation of this document and all executed copies thereof; (2) execution of a signed statement; (3) an oral statement made in the presence of two persons; (4) a statement during a terminal illness or injury addressed to an attending physician, or (5) a signed card or document found on his person or in his effects.

Initial the line next to the statement below that best reflects your wishes. You do not have to initial any of the statements. If you do not initial any of the statements, your agent and your family will have the authority to make a gift of all or part of your body under Pennsylvania law.

_____ I do not want to make an organ or tissue donation and I do not want my agent or family to do so.

_____ I have already signed a written agreement or donor card regarding organ and tissue donation with the following individual or institution:

Name of individual/organization: ____________________________

_____ Pursuant Pennsylvania law, I hereby give, effective on my death (initial one)

_____ Any needed organ or parts.

_____ The following part or organs listed below:

For (initial one):

_____ Any legally authorized purpose.

_____ Transplant or therapeutic purposes only.

Note: A gift of the whole body shall be invalid unless made in writing at least fifteen days prior to the date of the death, or consent is obtained from the legal next of kin.
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
YOU HAVE FILLED OUT YOUR ADVANCE DIRECTIVE, NOW WHAT?

1. Your Pennsylvania Directive is an important legal document. Keep the original signed document in a secure but accessible place. Do not put the original document in a safe deposit box or any other security box that would keep others from having access to it.

2. Give photocopies of the signed original to your healthcare agent and alternate healthcare agents, doctor(s), family, close friends, clergy and anyone else who might become involved in your healthcare. If you enter a nursing home or hospital, have copies of your Directive placed in your medical records.

3. Be sure to talk to your healthcare agent and alternate, doctor(s), clergy, and family and friends about your wishes concerning medical treatment. Discuss your wishes with them often, particularly if your medical condition changes.

4. If you want to make changes to your Directive after it has been signed and witnessed, you must complete a new document.

5. Remember, you can always revoke your Pennsylvania Directive.

6. Be aware that your Pennsylvania document will not be effective in the event of a medical emergency. Ambulance personnel are required to provide cardiopulmonary resuscitation (CPR) unless they are given a separate order that states otherwise. These orders, commonly called an “out-of-hospital do-not-resuscitate orders,” are designed for people whose poor health gives them little chance of benefiting from CPR. These orders must be signed by your physician and instruct ambulance personnel not to attempt CPR if your heart or breathing should stop.

Currently not all states have laws authorizing non-hospital do-not-resuscitate orders. We suggest you speak to your physician for more information. Caring Connections does not distribute these forms.
Appendix A

Glossary

**Advance directive** - A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

**Artificial nutrition and hydration** – Artificial nutrition and hydration supplements or replaces ordinary eating and drinking by giving a chemically balanced mix of nutrients and fluids through a tube placed directly into the stomach, the upper intestine or a vein.

**Brain death** - The irreversible loss of all brain function. Most states legally define death to include brain death.

**Capacity** - In relation to end-of-life decision-making, a patient has medical decision making capacity if he or she has the ability to understand the medical problem and the risks and benefits of the available treatment options. The patient's ability to understand other unrelated concepts is not relevant. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court.

**Cardiopulmonary resuscitation** - Cardiopulmonary resuscitation (CPR) is a group of treatments used when someone’s heart and/or breathing stops. CPR is used in an attempt to restart the heart and breathing. It may consist only of mouth-to-mouth breathing or it can include pressing on the chest to mimic the heart’s function and cause blood to circulate. Electric shock and drugs also are used frequently to stimulate the heart.

**Do-Not-Resuscitate (DNR) order** - A DNR order is a physician’s written order instructing healthcare providers not to attempt cardiopulmonary resuscitation (CPR) in case of cardiac or respiratory arrest. A person with a valid DNR order will not be given CPR under these circumstances. Although the DNR order is written at the request of a person or his or her family, it must be signed by a physician to be valid. A non-hospital DNR order is written for individuals who are at home and do not want to receive CPR.

**Emergency Medical Services (EMS)**: A group of governmental and private agencies that provide emergency care, usually to persons outside of healthcare facilities; EMS personnel generally include paramedics, first responders and other ambulance crew.

**Healthcare agent**: The person named in an advance directive or as permitted under state law to make healthcare decisions on behalf of a person who is no longer able to make medical decisions.
**Hospice** - Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person's needs and wishes. Support is provided to the persons loved ones as well.

**Intubation** - Refers to "endotracheal intubation" the insertion of a tube through the mouth or nose into the trachea (windpipe) to create and maintain an open airway to assist breathing.

**Life-sustaining treatment** - Treatments (medical procedures) that replace or support an essential bodily function (may also be called life support treatments). Life-sustaining treatments include cardiopulmonary resuscitation, mechanical ventilation, artificial nutrition and hydration, dialysis, and other treatments.

**Living will** - A type of advance directive in which an individual documents his or her wishes about medical treatment should he or she be at the end of life and unable to communicate. It may also be called a “directive to physicians”, “healthcare declaration,” or “medical directive.”

**Mechanical ventilation** - Mechanical ventilation is used to support or replace the function of the lungs. A machine called a ventilator (or respirator) forces air into the lungs. The ventilator is attached to a tube inserted in the nose or mouth and down into the windpipe (or trachea).

**Medical power of attorney** - A document that allows an individual to appoint someone else to make decisions about his or her medical care if he or she is unable to communicate. This type of advance directive may also be called a healthcare proxy, durable power of attorney for healthcare or appointment of a healthcare agent. The person appointed may be called a healthcare agent, surrogate, attorney-in-fact or proxy.

**Palliative care** - A comprehensive approach to treating serious illness that focuses on the physical, psychological, spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering, and controlling pain and symptoms.

**Power of attorney** - A legal document allowing one person to act in a legal matter on another's behalf regarding to financial or real estate transactions.

**Respiratory arrest** - The cessation of breathing - an event in which an individual stops breathing. If breathing is not restored, an individual's heart eventually will stop beating, resulting in cardiac arrest.
Surrogate decision-making - Surrogate decision-making laws allow an individual or group of individuals (usually family members) to make decisions about medical treatments for a patient who has lost decision-making capacity and did not prepare an advance directive. A majority of states have passed statutes that permit surrogate decision making for patients without advance directives.

Ventilator - A ventilator, also known as a respirator, is a machine that pushes air into the lungs through a tube placed in the trachea (breathing tube). Ventilators are used when a person cannot breathe on his or her own or cannot breathe effectively enough to provide adequate oxygen to the cells of the body or rid the body of carbon dioxide.

Withholding or withdrawing treatment - Forgoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.
Appendix B

Legal & End-of-Life Care Resources Pertaining to Healthcare Advance Directives

LEGAL SERVICES
The Pennsylvania Department of Aging website has legal information and resources to assist individuals over the age of 60 and individuals with disabilities who have low to moderate incomes.

Individuals over the age of 60 with legal questions should contact the Area Agency on Aging (AAA) in their area.

Individuals can get legal information and advice about most issues, including:
- Advance Directives and Healthcare Planning
- Living Wills and Trusts
- Power of Attorney
- Civil issues and more

- Must be over 60
- Free for individuals with low to moderate incomes

To locate AAA in your area:
Call: 1-877-727-7529 or 1-717-783-1550
OR
For more information about visit their website: http://www.aging.state.pa.us/aging/

END-OF-LIFE SERVICES
The Pennsylvania Department of Aging can connect individuals over the age of 60 with programs and services available in their area.

Individuals over the age of 60 with low to moderate incomes can receive assistance through their Area Agency on Aging with programs and services to include, but not limited to:
- Legal Assistance
- Ombudsman
- Adult Day Care
- Meals and Transportation
- Drug programs and more

For more information about programs and services visit their website: http://www.aging.state.pa.us/aging/

For location of AAA in Pennsylvania, visit their website: http://www.aging.state.pa.us/aging/

OR
Call: 1-717-783-1550