CARING CONNECTIONS

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.

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:
- Learn about options for end-of-life services and care
- Implement plans to ensure wishes are honored
- Voice decisions to family, friends and healthcare providers
- Engage in personal or community efforts to improve end-of-life care

Visit www.caringinfo.org 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. Contributions to national hospice programs can also be made through the Combined Health Charities or the Combined Federal Campaign by choosing #11241.

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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 HI PAA 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.
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 Virginia Advance Medical Directive

This packet contains the *Advance Directive for Healthcare* which 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 Virginia Advance Medical Directive** lets you state your wishes about medical care in the event you develop a terminal condition, meaning it is probable that you will not recover from the condition and either your death is imminent or you are in a persistent vegetative state. This document also lets you name someone to make healthcare decisions on your behalf any time you are unable to make your own medical decisions, not only at the end of life.

*Note: This document will be legally binding only if the person completing it is a competent adult (at least 18 years old).*
Completing Your Virginia Advance Medical Directive

How do I make my Virginia Advance Medical Directive legal?

State law requires that you sign your Advance Medical Directive in the presence of two adult witnesses. Employees of healthcare facilities and physician’s offices who act in good faith may serve as witnesses.

It is your responsibility to notify your attending physician that you have made an Advance Medical Directive. If you are comatose, incapacitated or otherwise mentally or physically incapable of communication, any other person may notify the physician of your advance directive.

Whom should I appoint as my agent?

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

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

Should I add personal instructions to my Virginia Advance Medical Directive?

Yes. You can add additional instructions under the section “Other directions” on page 1. This is important because it is unclear when you would be considered “terminal” under Virginia law.

If you have appointed an agent, it is a good idea to write a statement such as, “Any questions about how to interpret or when to apply my Advance Medical Directive are to be decided by my agent.” We also urge you to talk with your agent about your future medical care and describe what you consider to be an acceptable “quality of life.”
Completing Your Virginia Advance Medical Directive (continued)

It is important to learn about the kinds of life-sustaining treatment you might receive. Consult your doctor for more information.

What if I change my mind?

You may revoke your Virginia Advance Medical Directive at any time by:

- signing and dating a written revocation,
- physically cancelling or destroying the document, or directing another to do so in your presence, or
- orally expressing your intent to revoke the document. Your revocation becomes effective when you notify your attending physician.

What other important facts should I know?

- Virginia law also allows you to file a health care power of attorney, Advance Medical Directive, or a declaration of an anatomical gift with the state Department of Health’s Advance Health Care Directive Registry. The Registry is a secure online central registry for health care directives. If you decide to submit your directives to the Registry, state law imposes a few additional requirements:
  - You must notarize your Directive prior to submitting it to the Registry.
  - You must provide your attending physician, legal representative or other person with the information necessary to access the directives.
  - You must notarize any revocation of a directive, before submitting it to the Department of Health. However, failure to notify the Department of Health of the revocation does not affect the validity of the revocation.

- If any of the terms of your Virginia Medical Directive conflict with the terms of an anatomical gift (organ donation), your physician and you must work to resolve the conflict. If you are unable or incapable of resolving the conflict, your agent must work with your physician to resolve the conflict.
I, ______________________________________________________, willfully and voluntarily make known my desire and do hereby declare:

If at any time my attending physician should determine that I have a terminal condition where the application of life-prolonging procedures would serve only to artificially prolong the dying process, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort care or to alleviate pain.

Other directions:

In the absence of my ability to give directions regarding the use of such life-prolonging procedures, it is my intention that this advance directive shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences of such refusal.
OPTION: APPOINTMENT OF AGENT (CROSS THROUGH IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE HEALTH CARE DECISIONS FOR YOU)

I hereby appoint ________________________________________________,

( primary agent)

of _____________________________________________________________

_______________________________________________________________

(address and telephone number)

as my agent to make health care decisions on my behalf as authorized in this document. If ___________________________________________________

( primary agent)

is not reasonably available or is unable or unwilling to act as my agent, then I appoint

_______________________________________________________________

(alternate agent)

of _____________________________________________________________

_______________________________________________________________

(address and telephone number)

to serve in that capacity.

I hereby grant to my agent, named above, full power and authority to make health care decisions on my behalf, as described below, whenever I have been determined to be incapable of making an informed decision about providing, withholding or withdrawing medical treatment. The phrase “incapable of making an informed decision” means unable to understand the nature, extent and probable consequences of a proposed medical decision or unable to make a rational evaluation of the risks and benefits of a proposed medical decision as compared with the risks and benefits of alternatives to that decision, or unable to communicate such understanding in any way. My agent's authority hereunder is effective as long as I am incapable of making an informed decision.
The determination that I am incapable of making an informed decision shall be made by my attending physician and a second physician or licensed clinical psychologist after a personal examination of me and shall be certified in writing. Such certification shall be required before treatment is withheld or withdrawn, and before, or as soon as reasonably practicable after, treatment is provided, and every 180 days thereafter while the treatment continues.

In exercising the power to make health care decisions on my behalf, my agent shall follow my desires and preferences as stated in this document or as otherwise known to my agent. My agent shall be guided by my medical diagnosis and prognosis and any information provided by my physicians as to the intrusiveness, pain, risks, and side effects associated with treatment or non-treatment. My agent shall not authorize a course of treatment, which he knows, or upon reasonable inquiry ought to know, is contrary to my religious beliefs or my basic values, whether expressed orally or in writing. If my agent cannot determine what treatment choice I would have made on my own behalf, then my agent shall make a choice for me based upon what he believes to be in my best interests.

OPTION: POWERS OF MY AGENT (CROSS THROUGH ANY LANGUAGE YOU DO NOT WANT AND ADD ANY LANGUAGE YOU DO WANT)

The powers of my agent shall include the following:

A. To consent to or refuse or withdraw consent to any type of medical care, treatment, surgical procedure, diagnostic procedure, medication and the use of mechanical or other procedures that affect any bodily function, including, but not limited to, artificial respiration, artificially administered nutrition and hydration, and cardiopulmonary resuscitation. This authorization specifically includes the power to consent to the administration of dosages of pain-relieving medication in excess of recommended dosages in an amount sufficient to relieve pain, even if such medication carries the risk of addiction or inadvertently hastens my death;

B. To request, receive, and review any information, verbal or written, regarding my physical or mental health, including but not limited to, medical and hospital records, and to consent to the disclosure of this information;
C. To employ and discharge my health care providers;

D. To authorize my admission to or discharge (including transfer to another facility) from any hospital, hospice, nursing home, adult home or other medical care facility for services other than those for treatment of mental illness requiring admission procedures provided in Article 1 (§37.2-800 et seq.) of Chapter 8 of Title 37.2; and

E. To take any lawful actions that may be necessary to carry out these decisions, including the granting of releases of liability to medical providers.

F. To make decisions regarding visitation. Subject to physician orders and policies or any institutions to which I am admitted.

Other powers of my agent:

Further, my agent shall not be liable for the costs of treatment pursuant to his authorization, based solely on the authorization.

OPTION: APPOINTMENT OF AN AGENT TO MAKE AN ANATOMICAL GIFT OR ORGAN, TISSUE OR EYE DONATION (CROSS THROUGH IF YOU DO NOT WANT TO APPOINT AN AGENT TO MAKE AN ANATOMICAL GIFT OR ANY ORGAN, TISSUE OR EYE DONATION FOR YOU.)

Upon my death, I direct that an anatomical gift of all or any part of my body or certain organ, tissue or eye donation may be made pursuant to Article 2 (§32.1-291 through 291.25) of Chapter 8 of Title 32.1 and in accordance with my directions, if any. I hereby appoint

____________________________________________________ as my agent, of

______________________________________________________________

(print the name, address and telephone number of your agent)

These may be the same as your primary agent

Upon my death, I direct that an anatomical gift of all or any part of my body or organ, tissue or eye donation following my death. I further direct that:

(address and telephone number of agent)
This advance directive shall not terminate in the event of my disability.

By signing below, I indicate that I am emotionally and mentally competent to make this advance directive and that I understand the purpose and effect of this document.

_______________________________________________________________
(date)                                                     (signature of declarant)

The declarant signed the foregoing advance directive in my presence.

Witnesses_______________________________________________________
Witnesses_______________________________________________________

Courtesy of Caring Connections
1731 King St., Suite 100, Alexandria, VA  22314
www.caringinfo.org, 800/658-8898
You Have Filled Out Your Advance Directive, Now What?

1. Your Virginia *Advance Medical 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 agent and alternate agent, 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 photocopies of your document placed in your medical records.

3. Be sure to talk to your agent and alternate agent, doctor(s), clergy, 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 documents after they have been signed and witnessed, you must complete a new document.

5. Remember, you can always revoke your Virginia Directive. If you revoke your Directive, make sure you notify your agent and alternate agent, your family and your doctors.

6. Be aware that your 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 “non-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 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
Virginia Department for the Aging provides a variety of services available to assist seniors, their families and caregivers. They can connect individuals over the age of 60 with moderate to low incomes with their local Area Agency on Aging (AAA), for legal referrals in their area.

Individuals can receive legal information and advice on most issues, including:
- Questions and answers about advance directives
- Civil issues
- Power of Attorney
- Living Wills and Trusts
- Social Security benefits and more

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

To locate AAA in your area:
Call toll free: 1-800-552-3402 or 1-804-662-9333

OR

The Virginia Department for the Aging also has a list of legal resources on their website for older individuals. To find out about services they provide, click on the following link: http://www.vda.virginia.gov

END-OF-LIFE SERVICES
Virginia Department for the Aging provides a variety of services available to assist seniors, their families and caregivers. They can connect individuals over the age of 60 with moderate to low incomes with their local Area Agency on Aging (AAA), for services and programs in their area.

AAA resources and services include, but are not limited to:
- Meals on Wheels
- Transportation
- Referrals to other service providers in their community
- Legal resources and more

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

To locate an AAA in your area and for more information about the services, visit their website:
http://www.vda.virginia.gov/findservices.asp

OR

Call toll free: 1-800-552-3402 or 1-804-662-9333