The GIFT
A Guide To Advance Care Planning
It’s the GIFT you give your loved ones...

Every day, we make dozens of choices for ourselves. Our friends and family learn these choices over time, remembering everything from our favorite colors to what drink to order for us at dinner. Yet when it comes to some of the most important choices we can make—choices about what we would want for our health care if we could not speak for ourselves—few of our friends and family can say for sure what our wishes are.

Deciding the kind of health care you want at the end of your life is called **Advance Care Planning, and it’s the greatest gift you can give your loved ones.**

Advance care planning is:

- Learning about possible decisions you may face during a health crisis or illness
- Making choices in light of what is important to you
- Talking about your decisions with loved ones and doctors
- Writing down your plans so they will be ready if needed

The goal of Advance Care Planning is for you to live well, in a way that is meaningful to you, for as long as you live.

**Why Plan Now?**

If you become unable to make your own decisions, and your wishes are not formally recorded, your physician will consult someone close to you about your care. They will rely on this person to try to **guess** your wishes. Don’t let a guess guide your health care! These questions are best considered, decided, and communicated to others in advance, long before there is a health crisis or illness.

*At the end of life, 1 in 4 elderly people are not able to make decisions about their care.*

*Source: New England Journal of Medicine, 2010*
FREQUENTLY ASKED QUESTIONS

Q: What is Advance Care Planning?
A: Advance Care Planning is making formal plans for the kind of health care you would want at the end of your life. It means knowing your treatment options and your values, talking with your loved ones, and recording your wishes.

Q: What is an Advance Directive?
A: Advance Directives are legal documents that formally record your future healthcare wishes and appoint a person to make healthcare decisions if you are not able to speak for yourself.

Advance Directive forms vary from state to state. In North Carolina, there are four documents that you may use: Living Will, Healthcare Power of Attorney, Do Not Resuscitate (DNR) order, and Medical Order for Scope of Treatment (MOST). These documents cover various aspects of end of life care.

Q: Why bother with an Advance Directive if I just want my family to make the necessary decisions for me?
A: You can give your family specific instructions on your medical decisions, which will save them from a great deal of stress. First, you can designate the specific person (or persons) you trust to carry out your wishes—your spouse, sibling, child, etc. In fact, this person does not have to be a family member at all.

Second, you can make your views known on a variety of circumstances. For example, your family may have no idea what you think about being on a breathing machine. Recording your wishes is a gift you can give the loved ones who are faced with making decisions about your care.

Q: What happens if I do not complete my own Advance Directives?
A: There is not a simple answer to this question. In general, physicians consult with families when the person cannot make decisions. You have undoubtedly seen terrible stories in the news where one family member is battling another over their loved one’s medical treatments (or lack of treatments); you may have seen or experienced a conflict like it firsthand. If you cannot speak for yourself, the only way to ensure your health care wishes will be carried out is to record them in a set of Advance Directives.
YOUR VALUES, VIEWS, AND BELIEFS

Your values, views, and beliefs are important guides in making choices about your life and your health care. Answering the questions below will help you begin the process of creating your own Advance Care Plan.

What Is Most Important to Me?

Check any that apply.

☐ Being able to recognize and communicate with family and friends
☐ Thinking well enough to make everyday decisions
☐ Being conscious and aware of what is happening around you
☐ Living without life-support machines
☐ Being able to care for yourself independently (bathing, dressing, feeding)
☐ Being able to move about
☐ Engaging in favorite activities, like listening to music, reading, etc.
☐ Other(s)  ____________________________________________________________

Would you feel that life would still be living if you could not enjoy most or all of these things? Why or why not?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

Thinking About Possible Health Care Choices

1. If you were unable to make health care decisions for yourself, who would you like to make decisions for you? (List up to three individuals)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

2. If you found out you were going to die soon, what things would you want to take care of first? (Ex: Deal with a business or financial concern, handle a legal matter, mend a friendship, etc.)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
3. Do you have religious or spiritual ways to prepare for the end of life? If so, what are they?
________________________________________________________
________________________________________________________
________________________________________________________

4. Are there health problems that you think would be worse than death, such as living with great pain, total physical dependency, or not being able to recognize or communicate with family and friends? If so, please list those things below.
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

5. If you were dying, which of the following approaches to treatment would you prefer? You may choose more than one. (If you choose more than one, please show your order of preference with 1 being the most important.)

☐ Your main wish would be for care that allows you to be comfortable, peaceful, and free from pain (including hospice care if possible).

☐ You would want to go to the hospital for some treatment if needed for comfort, but you would not want to be connected to life support machines.

☐ If it were unclear whether a trial of life support treatment would improve your chances of living, you would like to have a brief period of treatment at the hospital, but would like the treatment stopped if you did not improve.

☐ You would like life support treatments to prolong your life as long as possible, even if those treatments made you uncomfortable.

☐ You would like to donate organs or tissues and would like life support treatments if needed for organ donation.

If you prefer, put your own ideas into words here:
________________________________________________________
________________________________________________________
________________________________________________________
________________________________________________________

73% of people surveyed said that not being able to communicate their wishes would be worse than dying.
Source: AARP End of Life Survey, 2003
6. If you were dying and became unable to eat, which of the following treatments do you think you would want?
   □ Tube inserted into stomach, nose, or mouth to feed you
   □ You would not want a feeding tube

7. Following your death, would you want to be an organ, eye, and/or tissue donor?  □Yes  □No

Other Notes

__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
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These worksheets are not legal documents, but they can be attached to your Advance Care Planning forms to help show your thoughts. Don’t forget to share these ideas with your family and your doctor.
THE ADVANCE DIRECTIVE FORMS

In the previous section, you considered the kinds of care you would want at the end of life, taking into account your personal values, views, and beliefs. The next step is to formally record your choices. To do so, you will need one or more documents that will make up your Advance Directives.

In North Carolina, there are four documents that cover different aspects of Advance Care Planning:

- Living Will
- Health Care Power of Attorney (HCPOA)
- Do Not Resuscitate (DNR)
- Medical Order for Scope of Treatment (MOST)

Any adult over the age of 18 who has the capacity to make their own decisions may create these documents. While each one is a binding legal document, you **always** have the option to create new plans as your life circumstances change.

**Living Will**
Questions about how and when to prolong your life are answered in a Living Will (also called the Advance Directive For a Natural Death). A Living Will only comes into effect when your physician and one other physician determine that you meet **ONE** of the following criteria:

- You are incurably sick with an irreversible condition that will result in your death within a short period of time.
- You are unconscious and your physician determines that it is highly unlikely you will regain consciousness.
- You have advanced dementia or a similar condition, resulting in you being unable to speak for yourself.

In a Living Will, you are able to tell your physician whether or not to use life-prolonging treatments like breathing machines (respirators or ventilators), or whether you want artificial nutrition and hydration (feeding tubes, IVs).

A **Living Will** must be signed by you in the presence of a Notary Public and two witnesses in order to be valid. Creating a Living Will does not prevent you from speaking for yourself as long as you have the capacity to do so.
Health Care Power of Attorney (HCPOA)
A Health Care Power of Attorney is a legal document in which you can name up to three people as your health care agent(s) to make medical and mental health decisions for you if you are unable to decide for yourself. The order in which you name the individuals determines who will be your primary spokesperson. You should choose someone you trust to be your health care agent, and discuss your wishes with him or her before putting them into writing.

The HCPOA only goes into effect if you are unable to make decisions or communicate those decisions for yourself.

A North Carolina HCPOA must be signed by you in the presence of a Notary Public and two witnesses in order to be valid. As with the Living Will, creating a HCPOA does not prevent you from speaking for yourself as long as you have the capacity to do so.

Do Not Resuscitate (DNR)
A Do Not Resuscitate form informs health care professionals that you do not desire to be revived in any manner if your heart stops. This includes CPR, shock, or intubation. The form is bright yellow and is designed to be seen: it should be posted somewhere near the patient so health care providers will spot it immediately.

Your doctor must sign the DNR for it to be valid. Copies of the form are not valid—only the original form is honored.
Medical Order for Scope of Treatment (MOST)
The Medical Order for Scope of Treatment (MOST) is the newest health care planning document in North Carolina. The hot pink form addresses many health care decisions in detail, including CPR, antibiotics, artificial nutrition, and more. MOST forms are typically utilized by those with chronic health issues, like congestive heart failure.

MOST is a physician’s order, and must be signed by a doctor. It also requires your signature or the signature of your health care power of attorney. MOST does not need to be notarized, but must be updated, reviewed, and signed each year by a physician or nurse practitioner in order to be valid.

Where Can I Find These Forms?
Living Will and Healthcare Power of Attorney: View the forms online at the NC Secretary of State’s website (www.secretary.state.nc.us/ahcdr/). To be official, the forms must be notarized and witnessed. Ask your attorney or end of life care provider for more information.

DNR and MOST orders: Because these are official physician’s orders, they must be completed and signed by your doctor. Contact your physician and ask for help with Advance Care Planning.
PLANNING FOR COMFORT CARE

In addition to the legal documents, your Advance Care Plan can include anything that you would find comforting during a health crisis or at the end of life. To a health care provider, the term “comfort care” means not only relieving pain and symptoms, but caring for your physical, emotional, social, and spiritual needs. Answer the following questions to help your loved ones understand what you need to be comfortable.

Medication—Check the box next to one of the answers below.

- I prefer that enough pain medication be given to me to keep me comfortable, even if this means I am not fully aware of what is going on.
- I prefer that I be medicated for pain but also want to be aware of my surroundings and what is going on. I understand this may mean my pain control may not be complete.

Non-Medicinal Comfort Measures—Choose any you would find comforting.

- Personal hygiene, such as baths or sponging, mouth care, etc.
- Turning and repositioning
- Back rubs, massage, and/or healing touch
- Other ____________________________

Special People—Record the names of special people or pets whose presence would comfort you.

Family members ____________________________

Members of my faith community ____________________________

Other special people or pets ____________________________

Someone to be with me at the time of my death if possible ____________________________

Environment—Where would you be most comfortable?

- I would like to be at home if possible.
- I would like to be at the hospital. (Which? ____________________________)
- I would like to be at a health care facility. (Which? ____________________________)
- If possible, please take me outdoors.
- Other ____________________________

______________________________
**In The Room**—Consider ways to make your surroundings more comfortable.

I would like pictures of these loved ones to be nearby: ________________________________

Flowers — Favorites: ________________________________

Objects that are special to me: ________________________________

Candles—Scents: ________________________________

Television favorites or times of day: ________________________________

Types of music or radio stations: ________________________________

Specific music selections: ________________________________

Readings—Religious: ________________________________

Traditional readings: ________________________________

Poetry, books, etc.: ________________________________

Prayers: ________________________________

Religious rituals or traditions ________________________________

Other ________________________________

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97% of people who asked for comfort care in their Advance Directives received the care they wanted.

*Source: New England Journal of Medicine, 2010*
OTHER CONCERNS

Estate Planning
Just as Advance Directives record your wishes for health care at the end of life, Estate Planning documents record your legal and financial wishes at the end of life.

A Will allows you to name your assets to specific recipients. Once recorded in a Will, your wishes are treated as law. There are also tax advantages for your estate when you create a Will. If you leave no Will behind, it can be costly to your heirs and leaves you no say over who gets your assets.

A Power of Attorney appoints an official agent to manage your financial affairs if you are unable to speak for yourself. Your agent will be able to sell property, make investments, etc. just as you might do on a day-to-day basis.

An Irrevocable Trust helps preserve and pass down your assets. Assets like property or investments that are placed in an Irrevocable Trust still earn interest for you, but are not considered personal assets for estate tax purposes or by Medicaid during the application process. This can result in substantial savings for you and your heirs/beneficiaries. In addition, an Irrevocable Trust allows you a private way to name who shall inherit each asset upon your death. You are able to keep details about your assets and your beneficiaries private—no one outside of your legal team and beneficiaries will be able to access your information. This is in stark contrast to a Will, which is open for the public to see and read. An Irrevocable Trust is a highly complex legal instrument and should be drafted by an attorney.

Consult your attorney and/or financial planner to begin the Estate Planning process.

Other Important Documents
Along with your Advance Directives and Estate Planning forms, you may want to keep other important documents in the same place for future reference:

- Life Insurance
- Organ Donation
- Funeral Pre-Planning
- Burial Insurance
- Banking Information

Leave a Legacy...
Naming Burke Hospice, a 501(c)(3) nonprofit, in your Will or Trust can benefit your estate. Ask your financial advisor or attorney for more information.
YOUR COMPLETED ADVANCE CARE PLAN

Sharing & Storing Your Documents
Make several photocopies of your completed Advance Directives, Estate Planning documents, and any worksheets from this book that will help express your wishes. Keep the original documents in a safe but easily accessible place, and tell others where you put them; you can note on the photocopies the locations where the originals are kept. DO NOT KEEP YOUR ADVANCE DIRECTIVES IN A SAFE DEPOSIT BOX! In a time of crisis, other people may need access to them quickly.

Give photocopies of your documents to everyone who may need them:

• Your Healthcare Power of Attorney and alternates
• Your primary physician and specialists
• Other family members or friends
• Your hospital of choice, to keep on file

If you have surgery or are being admitted to a hospital, bring a copy with you and ask for it to be placed in your medical record.

North Carolinians also have the opportunity to file their Advance Directives with the Secretary of State’s online registry and access them securely via the Internet. Visit the NC Secretary of State’s website at [www.secretary.state.nc.us/ahcdr/](http://www.secretary.state.nc.us/ahcdr/) for more details.

Reviewing & Updating Your Directives
Ideally, your Advance Directives should be reviewed every few years, or after a major life event. The American Bar Association uses the “Five D’s” to help remember when you should re-examine your health care wishes:

• **Decade**—When you start each new decade of your life.
• **Death**—Whenever you experience the death of a loved one.
• **Divorce**—When you experience a divorce or other major family change.
• **Diagnosis**—When you are diagnosed with a serious health condition.
• **Decline**—When you experience a significant decline or deterioration of an existing health condition, especially when it diminishes your ability to live independently.

Advance Directives save your loved ones from stressing and guessing your wishes during a crisis... It may be the most important **GIFT** you ever give.
FURTHER RESOURCES

Burke Hospice & Palliative Care
Help with Advance Directives and end of life care planning.
Call for a free consultation: 828/879-1601
www.BurkeHospice.org

North Carolina Advance Health Care Directive Registry
File your Advance Directives with the NC Secretary of State, then access them securely from anywhere with an internet connection.
www.secretary.state.nc.us/ahcdr/

Caring Connections
A Service of the National Hospice & Palliative Care Organization
Includes downloadable Advance Directives for all 50 states.
www.caringinfo.org

American Association of Retired Persons
Informative videos and articles on Advance Directives, Estate Planning, end of life care, and more.
www.AARP.org

Special Thanks To
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• Providing compassionate, loving, and respectful Hospice and Palliative Care services
• Comprehensive medical care
• Bereavement and volunteer programs
• Counseling and spiritual support
• Medicare, Medicaid and most insurance accepted
• Local, independent non-profit, proudly serving our communities for over 30 years

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