



# Hospice

and Palliative Care of Greensboro

## Advance Care Planning

How to Plan for End-of-Life Decisions and Talk  
about it with Loved Ones

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*If your loved one is near end-of-life, and the doctors ask you  
to make decisions about their care, what would you do?*

*Lunch & Learn at the Lusk Center*

*A free workshop series to help you navigate complex care and health issues*



# What are Advance Directives?

**Advance Directives** are a set of directions that you give about the health care you would want if you ever lose the ability to make decisions for yourself.

A **Living Will** is where you state your wishes for your health care.

A **Health Care Power of Attorney** is where you name the person who you want to make medical decisions for you if you are unable.

## Where did Advance Directives come from?

There was no such thing as Advance Directives before the 1970's.

By the mid-1990's all states had passed laws to make legal the use of living wills and health care power of attorneys.

### **What changed?**

Advances in modern medicine and technology have drastically changed how, when, where and *if* we die. For much of human history, people commonly died of infections, injuries, or after fairly brief illnesses. Then, the 20<sup>th</sup> century brought us:

- penicillin, vaccines, and thousands of other medications
- blood transfusions, ventilators, feeding tubes, dialysis
- chemotherapy, radiation, surgeries, transplants.
- highways, hospitals, 9-1-1, CPR, EMS, and intensive care units

With these advances, we became able to respond to crises very quickly, and doctors became able to bring people back from the brink of death. They could now use machines to breathe, tubes to feed, dialysis to provide kidney function, etc. The intention: to “build a bridge” between life and death for the injured or ill person. As these persons heal, they can resume natural breathing and eating, and go back life as they knew it. Countless people have been able to live longer lives because of these advances.

### **Unintended consequences**

Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo were all young women who had a sudden medical crisis. For them, the ventilators, feeding tubes, etc. did not provide the bridge back to life. Instead, these women were left stranded in a “no-man’s land” -- somewhere between living and dying. Each had suffered brain death and would never

regain consciousness. All three “lived” for many more years, as their families – and society – struggled with the question of what to do in these situations.

- What happens when a person is on life support and has no hope of recovering?
- Once a person is on life support, is it ethical and acceptable to take those life supports away?
- Who makes this decision?

### ***The courts decide:***

The **Patient Self-Determination Act** is a federal law that was enacted in 1991. It established that every person has:

- The right to make their own health care decisions
- The right to accept or refuse medical treatment
- The right to make their wishes known about life-prolonging measures in a **Living Will**
- The right to name someone as their **Health Care Power of Attorney** to advocate for those wishes.

By law, hospitals, nursing homes, home health agencies, and HMO's must inform patients of these rights.

These legal changes were designed to **empower** individuals and to protect their rights.

# Why would I want Advance Directives?

- So you can say **now** what your wishes would be for end-of-life care.
- So you can have **who you want** as your representative if and when you can't speak for yourself.
- So you can **ease the burden** for your loved ones if they ever have to face this situation.

At some point in our lives, most of us will become unable to speak for ourselves. That's when doctors will turn to our loved ones.

Our loved ones won't know what decisions we would want made ***unless we have told them.***

Most of us never imagined that we would be asked by doctors to 'decide' about whether our loved ones will be kept alive or allowed to die naturally. It can be a deeply emotional and difficult moment. **But it is a reality of modern life.** We can help our loved ones be more able to face this moment if we have talked with them and completed our advance directives.

*"I have an advance directive, not because I have a serious illness, but because I have a family."*

- Ira Byock, M.D.

## When should I complete my Advance Directives?

**Now** – if you are over 18 years of age. The best time to complete these documents – **and discuss them with family** – is when there is no crisis at hand. The **worst** time to start this conversation is at the hospital when there is a medical crisis – when families are confused, scared and upset. If family members are not prepared, this situation can lead to deep and lasting conflict. And you will have missed your chance to help prepare them for, and guide them through, this moment.

***It always seems too early, until it's too late.***

# What decisions will I have to make?

- Do you want to appoint a Health Care Power of Attorney – a person to speak on your behalf and make medical decisions for you, when --*and only when* --you are unable to speak for yourself? (Yes or No)
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Note: You do not need to name a Health Care Power of Attorney. You can choose only to complete a Living Will.

Here are the decisions that your Health Care Power of Attorney can make:

- Starting or stopping life-prolonging measures
- Decisions about mental health treatment
- Choosing your doctors and facilities
- Reviewing and sharing your medical information
- Autopsies and disposition of your body after death.

Note: If you want a Health Care Power of Attorney, but you want to **limit some of these powers**, you may do so in Section Two of the Health Care Power of Attorney document.

**Your Health Care Power of Attorney would only become effective if a doctor determines that you are unable to make your own decisions.**

If you do not name a Health Care Power of Attorney, NC law dictates that your ‘decider’ will be (in this order): legal guardian, general POA; a spouse; a majority of your parents and adult children; a majority of your adult siblings; or a person who has an established relationship with you.

- If YES, who would be your first choice for Health Care Power of Attorney? Your second person?
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Note: Only **one** person can act as your HCPOA at a time. The second person serves as a back-up.

Your Health Care Power of attorney **must** be:

- **18** years or older and **have decision-making capacity**.
- **not** acting as your doctor or other health care provider.

He or she **should** be:

- someone you **trust** very much.
- someone who **knows you well**.
- **willing to honor your wishes** (even if they don't *agree* with your decisions).
- comfortable talking with doctors and **advocating** for you.
- **available** to represent you when needed.

- Would you want to donate your organs or tissues? (Yes or No).

If YES, you can give your Health Care Power of Attorney the power to do so if you initial that statement in Section 3.

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**Do you want to complete a Living Will –to state that you do not want to receive life-prolonging measures in certain situations? (Yes or No)**

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Note: You do not need to complete a Living Will. You can choose only to name a Health Care Power of Attorney.

**If YES, which situations do you not want to receive life-prolonging measures?**

**If you were unable to make your own medical care decisions and you have an incurable condition that will soon result in your death**

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**If you were unconscious and doctors were reasonably certain that you will never regain consciousness**

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**If you had advanced dementia or another condition that seriously and permanently impaired your ability to think**

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- Would you want tube feedings? If YES, initial Section 2.**

Note: Tube feeding is a life prolonging measure, but you have the option to indicate that this is one measure you choose to receive.

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- What if your Health Care Power of Attorney gives the doctor instructions that are different than the ones you gave in your Living Will?**

**Should the doctors follow your Living Will? Or  
Should they follow your Health Care Power of Attorney?**

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**This is an individual choice. Some people want to ensure that their wishes are followed exactly – perhaps because they want to spare family members the burden of decision-making. Others want their health care power attorney to have some leeway in making decisions – perhaps because they feel more confident if a loved one feels empowered to assess and act on whatever situation occurs.**

## ***Next Step: Having ‘the Conversation’***

You may want to fill out the forms to be sure that you understand them and are saying what you want. But...before you get these forms signed and notarized, you will need to have at **least** one conversation...

- With the person who you want to be your Health Care Power of Attorney and your back up person,
- You may also want to talk with your **doctor, clergy, or other persons whose opinion you value....** to help you make your decisions.

### **What needs to be said?**

### **How do I start that conversation?**

#### ***With the person(s) who you want to act as your Health Care Power of Attorney***

- Explain the role of Health Care Power of Attorney, if they don't know. You can show them pages 1 and 2 of the ***Advance Directive of North Carolina***, a copy of which is at the front pocket of this booklet.
- Ask if they are willing to act as your Health Care Power of Attorney
- Tell them about what you would want them to decide for you ... what treatments you might want, and what treatments you would not want.
- Explain your reasons. What is quality of life to you?  
At what point would life no longer have meaning or quality for you?  
Are there religious or spiritual values that guide your decisions?
- Ask if they feel comfortable and willing to follow through on your wishes.

## ***Suggested ways to start that conversation***

“I went to hear a presentation about completing Advance Directives, and it convinced me that this is an important thing to do for myself and the whole family. Can I talk to you about this?”

“I know that this isn’t easy to talk about, but if I get sick or have an accident — and can’t make medical decisions for myself — I’d like to share what would be important to me, so you could be my decision maker.”

“I’ve thought a lot about what happened to \_\_\_\_\_ (family, friend) when her mother went into the hospital. I want to make sure that you know what I would want if I was ever in that situation. I wouldn’t want you to feel burdened by any choices you might have to make on my behalf, without knowing what I’d want.”

After a movie or news story: “That’s not what I would want if I was that person. I want to make sure that you know my wishes if that ever happened to me.”

## ***What if you want to ask your parent or other loved one to talk about their wishes?***

Many of the conversation starters suggested above can be adjusted and used to approach this subject with a parent or other loved one.

**You also can state the simple truth: You love them. You worry about their well-being. It makes you scared and uncomfortable to even think about them being in a medical crisis....but it scares you even more to think that you might have to make decisions for them without knowing what they would want in these situations.**

It can be helpful to tell them that you have completed – or plan to complete – your own Advance Directives. Share your own thoughts about what you would want.

# Checklist for Making Advance Directives

- \_\_\_1. Get copies of an NC Living Will and HCPOA

**You have a one copy at the back of this packet.** You may make as many copies as you want. You may also get them by calling HPCG at 336-621-5565, or by going to the HPCG website:

<https://www.hospicegso.org/i-am-living-with-an-illness/patient-resources/>

- \_\_\_2. Review the decisions you will need to make.
- \_\_\_3. Talk to the one or two persons you want to be your Health Care Power of Attorney.
- \_\_\_4. Talk to your doctor if you want to discuss these issues with him or her.
- \_\_\_5. Seek out spiritual advice if that helps with your decisions.
- \_\_\_6. Complete the Advance Directives document –*BUT DO NOT SIGN THE LAST PAGE!!*
- \_\_\_7. Arrange to go to a public notary.

You often can find notaries at your bank, credit union, UPS store, or hospital. You may also know a notary public in your neighborhood or faith community. Ask if there is a charge for notarizing.

You will need to have two people witness you sign the documents. Witnesses cannot be related to you by blood or marriage, nor can they be persons who will inherit anything from your estate. Your health care providers cannot be witnesses as well.

You may ask the notary public if they can provide witnesses for you.

\_\_8. Once you have signed your documents...

Make copies. Give one to each of the following:

- your Health Care Power of Attorney
- your back-up Health Care Power of Attorney
- any other family members who would be involved if you were facing a medical crisis
  
- your doctor(s)
- your lawyer

Keep the original in an easy-to-find place. A bank safety deposit box is NOT a good place to keep it, as banks are closed on weekends and evenings.

Suggestions:

- top desk drawer
- glove compartment
- email it to yourself
- take a picture and keep it on your cell phone.

### ***One more VERY IMPORTANT thing to do***

You have had conversations with the one or two people who will be your Health Care Power of Attorney.

**Now it is time to share your advance directive wishes with other family members who would be involved if you were in a medical crisis.**

As you give them a copy of your completed advance directives, talk with them about it. If your goal is to give guidance and support to your family in a medical crisis, then it is crucial that all family members have been informed of your wishes. **NOT telling all loved ones is the single most common mistake that people make.** This oversight can cause great damage and hurt among family members.

# Frequently Asked Questions

## ***When would my Advance Directive be used?***

When and only when, you are unconscious or mentally incapacitated – and therefore unable to make your own decisions. If you regain consciousness or capacity, you again take charge of your health care decisions. A doctor makes these determinations.

## ***Do I need a lawyer to make these directives legal?***

No. In North Carolina, you only need to have these documents notarized and witnessed. If you prefer to engage a lawyer, that is your choice.

## ***What happens if I have a life-threatening emergency?***

You will be treated with life-sustaining measures until your Advance Directives are made available. Then your wishes will be followed.

## ***What if I want to change my Advance Directives?***

You may change your Advance Directives any time, as long as you have capacity. Simply destroy your old Advance Directive (and the copies). Complete new Advance Directives and distribute them to loved ones and your doctor. The document with the most recent date will be the valid one.

## ***Can I put these documents away forever?***

No. You should review and update your Advance Directives periodically. Use the Five D's as a guide:

**Decade.** Look at them at least once a decade

**Death.** Does the death of a loved one prompt you make any changes?

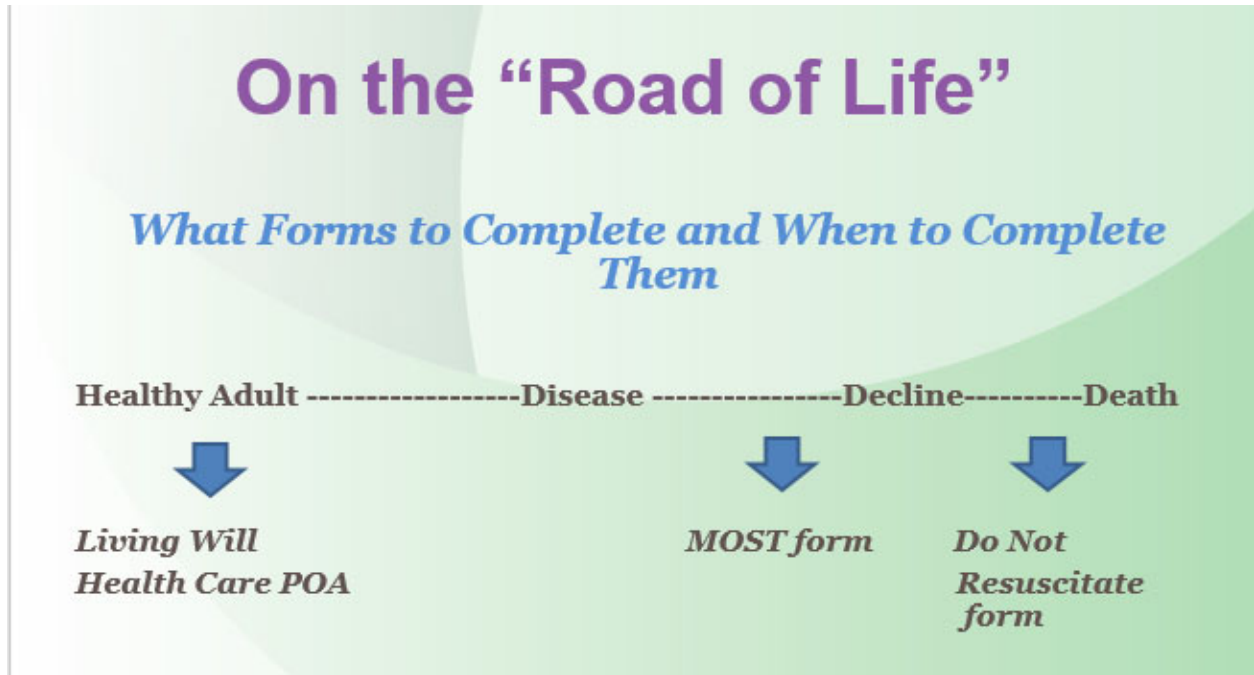
**Divorce.** Might you want to change your health care agent?

**Diagnosis.** Does a new diagnosis make you rethink the types of care you want?

**Decline.** Does declining health prompt you to rethink your care choices?

# What about other Advance Directives? Do I need to complete them as well?

If you are in good health, you probably do not need other advance directives right now. However, as you grow older, or as you develop serious medical conditions or illnesses, you may want to talk to your doctor about completing other medical advance directives.



## ***Most Forms (also called POLST forms in some states)***

A MOST (Medical Order for Scope of Treatment) form is a **doctor’s order**. This is a document that you would complete *with your doctor*.

Its purpose: to help you and your doctor decide and define what your goals of care are, as your disease progresses. This form is usually helpful when you are seeking less curative or aggressive treatments, and wanting to focus more on comfort and quality of life.

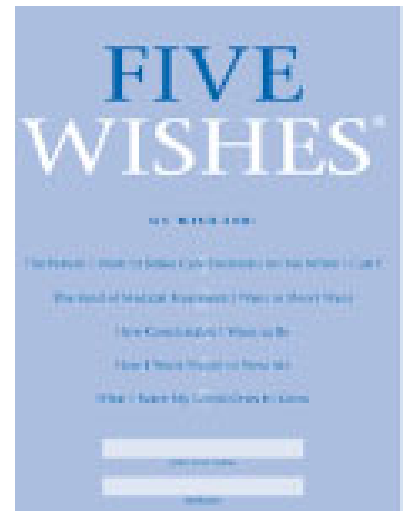
**MOST FORM WITH PATIENT/RESIDENT WHEN TRANSFERRED OR DISCHARGED**

## ***Do Not Resuscitate (DNR) Forms***



A Do Not Resuscitate form is also a **doctor's order**. This is an order that the doctor will sign after discussing with the patient or the patient's family/representatives. This order is written when the doctor determines that CPR, cardio-pulmonary resuscitation, would not be a viable choice for a patient. In other words, the patient is at end of life and CPR would be a futile effort.

You may hear of an advance directive called Five Wishes. This is an alternative living will and health care power of attorney document. It serves the same purpose as the NC Living Will and Health Care Power of Attorney. The differences: it is designed to be more user friendly, and it allows you to express more personal wishes – how you want people to treat you, and what you want your loved ones to know. Five Wishes also fulfills the requirements for advance directives that are set forth by NC Law.



### ***My Wishes (for teenagers)***



*My Wishes* is **not** a legal advance directive. But it can be a helpful tool for families with a **seriously ill child or teen**.

This booklet is written in everyday language to help children express how they want to be cared for if they become seriously ill. Like Five Wishes, *My Wishes* helps begin conversations among children, parents and caregivers.



## As we go forward...there will need to be more conversations.

Why? Because our Advance Directives only let you state your wishes when you are no longer conscious or have capacity to make your own decisions. ***But there are also many decisions you will have to make along the path of decline or illness.*** Medical advances will continue to offer more and more treatments to stave off death. More and more ways to keep our hearts beating. So, we may find ourselves in situations where we sometimes wonder if, in fact, there is a fate worse than death. We may question if there is any value to the medical care that is being offered.

As human beings, we have a strong will to live. Most of us are not comfortable talking about dying. In the 'olden days,' there were fewer reasons to talk about dying. In modern times, there are important reasons to find the courage to talk about dying.

- Because we may be offered care options that might offer us more time ***or might shorten*** our lives if the treatments are not effective.
- Because we may be offered care options that gives us unbearable or unacceptable quality of life
- Because we have come to recognize that the doctors cannot make medical care ***decisions*** for us. They can only offer us medical ***advice***.
- **Decisions about treatment are not simply medical choices. We are not just physical beings. We also are beings with unique spirituality, philosophies, passions, emotions, family, and friends. Only we know what gives our lives meaning, and when it no longer has meaning.**
- When facing an illness, we can get overwhelmed by how little control we have. But we can have ***more control*** if we are able and willing to ***talk*** with our loved ones and doctors, ask questions, and to make decisions based on our understanding of care options. We can be more true to ourselves and loved ones if we can openly talk about our situation, and make decisions based on what matters to us.

***“We [doctors] have been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being.***

***And well-being is about the reasons one wishes to be alive.***

***Dr. Atul Gawande***

# A Guide to Making Medical Decisions for Yourself or Your Loved One

Questions you may ask *yourself or loved one* to clarify your needs and wishes as you face a serious illness

1. What do I need to know and understand about this illness?
2. What are my concerns for the future?
3. What are my goals and priorities?
4. What outcomes would I find unacceptable?  
What am I willing to sacrifice or not?
5. Even with a serious illness, what would a “good day” be?

*These questions (slightly amended) are recommended by Dr. Atul Gawande in his book, **Being Mortal**. For more information, you may want to read his book, or go online to watch his interview on **Frontline**.*

Questions you may want to ask *your doctor* when you are faced with medical decisions

1. What are my choices for treatment? What *purpose* does it serve?
2. What is the best case scenario with this treatment? How much improvement? How much time might I gain?
3. What is the worst case scenario with this treatment? What side effects or risks? Might it shorten my time or negatively impact my quality of life?
4. What would the “no treatment” option look like? How might my situation look? Symptoms? Concerns? Amount of time I might have?
5. Can we take some time to consider care options? How much time? When would it be “too late?”

# Let's Stay in Touch

## Contact HPCG.....

*If you want help with your **Advance Directives**.*

We can set up a consultation appointment, or we can talk by phone.

*If you want a **speaker** for your club, work or faith group*

An HPCG representative can speak about a range of topics:

- Advance Directives
- Hospice Care
- Palliative Care
- Understanding Grief and Loss
- Caregiver Coping
- When Grief and Loss are Part of the Job

*If you want to schedule a discussion about **Being Mortal**.*

We can facilitate a book club discussion of Atul Gawande's bestseller, **Being Mortal**, or a viewing and discussion of the **PBS Frontline Being Mortal** documentary.

*If you think you or a loved one might benefit from a **palliative care consultation**.*

HPCG offers palliative care consultations in the home and at long-term care facilities. Call or check our website for more information.

*If you have questions about **Hospice care**.*

*If you want **grief counseling**, a grief support group or grief education. If your child needs **grief counseling**.*

*If your child is seriously ill, and needs **Kids Path CAP-C services or hospice care**.*

**336-621-2500**

**[www.hospicegso.org](http://www.hospicegso.org)**