The Carolinas Center works to promote excellence in care of people with advanced illness through high quality palliative, hospice and end of life care. Since 1977, we have supported providers of hospice and palliative care in North and South Carolina. Through education, advocacy, technical assistance and innovative leadership, we help all providers fulfill their missions of delivering exceptional care to individuals with advanced illness, and to their caregivers and families.

Please contact us for additional copies of this family guide, or for membership information if you would like to join us in our efforts.

Phone: 800.662.8859 • email: info@cchospice.org • website: www.cchospice.org
Isn’t It Time We Talk? is dedicated to helping families talk about their preferences for health care treatment in the future. It is also designed as a guide for you to think about and record your thoughts as you consider health care at different stages of your life. Ultimately, this planning guide is about your voice being heard and your choices being honored.

The information and worksheets in this guidebook are designed to walk you through conversations and decisions about your preferences for future health care. They are not legal documents but can (and should) be shared with your loved ones and your doctor when discussing your wishes. The legal documents you need to complete are noted on page 26.

We are aware that this guide cannot cover all the questions you may have, or all the decisions you and/or your family might face. It cannot address all the emotions or fears that might surface. What it can do is help you begin talking with your family members, selected friends, health care providers*, faith leaders, and others who might be important to you.

This guide will help you start to think about questions like:
• Who will speak for me if I can't speak for myself?
• If so, what would I want them to know?

Advance care planning is about giving your family the gift of conversation, and making a plan so that they know what you want. If you do not have a plan for care and treatment, neither your health care providers nor your family will know your wishes. This could result in uncertainty, disagreement, stress, anxiety, delay, and regret among your loved ones.

Now is the time to talk.
That is how we care for each other.
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Throughout this guide, any word marked with* is defined in the glossary on page 17.
What is Advance Care Planning?

We all make decisions every day, both simple and complicated. We plan ahead for expected events such as vacations, a wedding, or buying a house. It is just as important to plan ahead for the health care you want in the future and at the end of life. Advance Care Planning (ACP) involves making decisions about that care.

**Advance Care Planning is:**
1. Understanding possible future health care choices
2. Thinking about your choices in light of what is important to you
3. Talking about your decisions with loved ones, spiritual advisers, and your doctors
4. Putting your plans in writing by completing advance directives, so that they will be ready when needed

This planning guide walks you through these 4 steps so that you can give your future health care as much thoughtful planning as you do other important decisions in your life.

Why is Advance Care Planning Important?

- Decisions like these are best made before there is a health crisis.
- Advance care planning is not a single conversation or a one-time signing of forms. Your plans may change as your situation changes. You can make additions or changes as the years go by.
- Having these conversations and putting your wishes into writing is a gift to those who love you. It gives them the permission and ability to give you the care that you want if you cannot speak for yourself.

*The goal of ACP is for you to live in a way that is meaningful to you for as long as you live.*
Consider the Myths

“Only old people need an advance directive.”

No matter what the state of your present health, a change such as an accident or a serious illness could occur. Preparing for such a change is important for everyone, no matter how old or young, or how sick or well they may be. Talking about your preferences for future health care is a part of this preparation. What we think our loved ones want — and what they think we might want — is often wrong.

“My doctor, or my family, knows what I want.”

You may be right, but it would take the burden off them if you had a specific conversation about your decisions. Then, follow up with a copy of your advance directives that puts what you want into writing. A combination of talking and documenting is the best plan!

“Advance Care Planning costs a lot of money.”

You can get advance health care directives for free from health care providers, or print them from the websites noted on pg. 26.

You could pay an attorney to help you complete the forms, or get help from appropriately trained staff at your local physician’s office, hospital or hospice organization. There may be a small cost for a notary’s services, which are required on some advance directive forms. Ultimately, though, it is not a costly process.

“An advance health care directive means I won’t get any more treatment.”

Advance Directives are not “no CPR” orders. They allow you to decide how much or how little treatment you want in a wide range of medical situations. Putting your decisions in writing helps ensure that you get the care and treatment you want.

“If I go into hospice care, I am going to die immediately.”

Hospice is designed for seriously ill individuals who have six months or less to live if their illness continues on its current path. However, people often live longer than six months while receiving hospice care. Several studies have actually shown that patients receiving palliative care and hospice live longer than nonhospice patients receiving more aggressive care.1,2

“If I have a financial power of attorney, I don’t need a health care power of attorney.”

Most of the time these are separate legal documents.

“If I name someone as my health care agent, I will lose control of my care.”

Advance directives only go into effect when you can no longer communicate or make decisions. Naming a health care agent helps ensure that your wishes will be respected.
Consider the Facts

60% of people say that making sure their family is not burdened by tough decisions is “extremely important.”

56% have not communicated their end-of-life wishes.

Source: Survey of Californians by the California HealthCare Foundation (2012)³

89% of people say doctors should discuss end-of-life care issues with their patients.

17% report having such conversations with their doctors.

Source: Kaiser Family Foundation (2015)⁴

75% of people prefer to die at home.

Only 37% die in the location of their choice.

Source: Journal of Hospital Medicine (2013)⁵

82% of people say it’s important to put their wishes in writing.

23% have actually done so.

Source: Survey of Californians by the California HealthCare Foundation (2012)³

Think about a family member or close friend who has died. What is it about that experience that sticks out most in your mind? What would you want to be different for you and your loved ones?

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________

______________________________________________________________________
Understanding Future Health Care Choices

Now that we know how important it is to have these conversations at every stage of life, let’s think through some potential health care situations. These are designed to show the importance of early and ongoing decision-making, and to think about health options you might face someday. As you consider each situation, you might also like to write down any thoughts, feelings or questions that come to mind.

A healthy person with no chronic illness or problems:

- You are diagnosed with an advanced cancer. Important treatment choices need to be made, but you are quickly becoming too sick to make them. Who should make these decisions?
- You were in a head-on collision resulting in a brain injury and have been on a ventilator* for three weeks. The doctors say that there is no hope for recovery. Your family disagrees about the best decisions to make.

A person with a chronic illness:

- Your father has advanced Alzheimer’s disease and is having trouble swallowing. He never gave specific instructions or talked with you about whether or not he would want artificial feedings*. You must weigh the risks and benefits of a feeding tube and decide whether to have one inserted or not.
- You are diagnosed with an advanced cancer. Important treatment choices need to be made, but you are quickly becoming too sick to make them. Who should make these decisions?
- You were in a head-on collision resulting in a brain injury and have been on a ventilator* for three weeks. The doctors say that there is no hope for recovery. Your family disagrees about the best decisions to make.

A person with a terminal illness:

- You have advanced liver disease. You know that you are probably dying and you want every possible treatment so that you may see your son get married in three months. What should you tell your health care agent* now about your future treatment options?
- Your father has advanced Alzheimer’s disease and is having trouble swallowing. He never gave specific instructions or talked with you about whether or not he would want artificial feedings*. You must weigh the risks and benefits of a feeding tube and decide whether to have one inserted or not.

Begin advance care planning by looking at your health now, and start thinking about what you would want if your health were to worsen. The next four pages are worksheets to help you reflect on what’s important to you and what sort of care you might want for different health care situations. There’s also a guide for choosing a health care agent — someone who will speak for you and your wishes if you are unable to speak for yourself.

Feel free to take your time with these exercises, and remember that this type of planning is an ongoing process. It’s impossible to figure out every possible situation you might face, but by starting these difficult conversations now, you will lessen the stress of decision making — for both you and your loved ones — if you become seriously ill or injured.

A Family Guide to Health Care Decision Making — 7
Your beliefs, traditions, and values are important guides when making choices throughout your life, including choices about advance care planning. Your answers to the questions below will help guide you, your doctor, and your loved ones in deciding which treatments are best for you.

What brings joy and meaning to my life?

__________________________________________________________________________
__________________________________________________________________________

What religious or spiritual beliefs give me support and guidance?

__________________________________________________________________________
__________________________________________________________________________

What worries, if any, do I have about my health right now?

__________________________________________________________________________
__________________________________________________________________________

What kind of care would I want if my life changed because of illness or injury?

__________________________________________________________________________
__________________________________________________________________________

What are my fears, if any, about the dying process?

__________________________________________________________________________
__________________________________________________________________________

Who would I want to be with me if I were dying?

__________________________________________________________________________
__________________________________________________________________________

Where would I want to be if I were dying?

__________________________________________________________________________
And What Makes Life Worth Living

Thinking about your abilities and priorities will help guide your treatment choices. It will also help your health care agent* understand your wishes. As you read through the list below, consider what “quality of life” means to you, and how it might change if you become very ill.

<table>
<thead>
<tr>
<th>Check one of the boxes on the right that best describes how you would feel if you were:</th>
<th>LIFE LIKE THIS WOULD BE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Difficult but acceptable</td>
</tr>
<tr>
<td>Unable to walk but could get around in a wheelchair</td>
<td></td>
</tr>
<tr>
<td>Unable to leave home</td>
<td></td>
</tr>
<tr>
<td>In pain most of the time</td>
<td></td>
</tr>
<tr>
<td>Uncomfortable most of the time (nausea, diarrhea, shortness of breath, etc.)</td>
<td></td>
</tr>
<tr>
<td>Depressed or “blue” most of the time, no matter what’s going on that day</td>
<td></td>
</tr>
<tr>
<td>Fed through a feeding tube</td>
<td></td>
</tr>
<tr>
<td>Dependent on a breathing machine, which prevents you from speaking</td>
<td></td>
</tr>
<tr>
<td>On constant dialysis*</td>
<td></td>
</tr>
<tr>
<td>Dependent on someone to care for you 24 hours/day</td>
<td></td>
</tr>
<tr>
<td>Unable to control your bladder</td>
<td></td>
</tr>
<tr>
<td>Unable to control your bowels</td>
<td></td>
</tr>
<tr>
<td>Unable to think clearly and confused most of the time</td>
<td></td>
</tr>
<tr>
<td>Unable to recognize family or friends</td>
<td></td>
</tr>
<tr>
<td>Unable to talk and be understood by others</td>
<td></td>
</tr>
<tr>
<td>In a condition that caused your family severe worry or stress</td>
<td></td>
</tr>
<tr>
<td>In a condition that caused your family severe financial burden</td>
<td></td>
</tr>
<tr>
<td>Other:</td>
<td></td>
</tr>
</tbody>
</table>

• If you checked “worth living, but just barely” for more than one factor, would a combination of these factors make your life “not worth living?” If so, which factors?
• Does “not worth living” mean that you would rather die than be kept alive?
• What information or people do you need to help you decide how you feel about a situation?

Adapted from *Your Life, Your Choices* 6 and Messinger-Rapport et al (2009) 7
Personal and Spiritual Beliefs

Many people have special personal or spiritual beliefs that they want to have respected when making treatment decisions. Consider talking to a spiritual advisor or member of your faith about advance care planning.

**What are your beliefs?**

For each statement below, check one of the boxes (Yes, Not Sure, or No) to indicate whether you agree. Use the space at the bottom to explain and clarify your beliefs.

| I believe that it is always wrong to stop treatments that could keep me alive. | Yes | Not Sure | No |
| I believe that it is wrong to not provide artificial nutrition and hydration,* even if I am terminally ill or in a permanent coma. | Yes | Not Sure | No |
| I would like to have my spiritual advisor consulted regarding any difficult health care decision that must be made on my behalf. | Name: |
| I believe in less clinical forms of treatment, such as healing through prayer, acupuncture, or herbal remedies. I want the following treatments included in my care: | Yes | Not Sure | No |
| I believe that controlling pain is always important, even if the pain medications make me less alert. | Yes | Not Sure | No |
| I believe that my loved ones should take their own interests into consideration, as well as mine, when making health care decisions on my behalf. | Yes | Not Sure | No |
| I believe that my loved ones should consider the costs of treatments when making health care decisions on my behalf. | Yes | Not Sure | No |

Adapted from *Your Life, Your Choices*®

Additional beliefs and/or explanations for my beliefs:

______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
______________________________________________________________________
Choosing a Health Care Agent*

Deciding who will speak for you if you are unable to make decisions or to communicate is one of the most important parts of advance care planning. Consider your goals, fears, and wishes listed on the previous pages as you think about a few people who you could trust to take on this responsibility. (Most legal documents designating health care power of attorney* allow you to name one primary agent and 1-2 alternates.)

Name 3 people you might want to be your health care agent:

1) _________________________  2) _________________________  3) _________________________

These 3 people must all be:
• Over age 18.
• Not your health care provider (e.g. your family doctor or nurse practitioner) or employed by your health care provider, unless this person is your spouse or close relative

This exercise will help you choose the best spokespersons for you. On the top of each column, write in the names of one or more people you’re considering to be your health care agent. Then place a check mark in the column under their name for each true statement.

Consider how important each attribute is to you when making your decision:

<table>
<thead>
<tr>
<th>Attribute</th>
<th>1</th>
<th>2</th>
<th>3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would be willing to speak on my behalf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would be able to act on my wishes and separate her/his own feelings from mine</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knows me well and understands what’s important to me.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will talk with me now about sensitive issues and will listen to my wishes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lives close by or could travel to be at my side if needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could handle the responsibility</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Will be available in the future if needed</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Would be able to handle conflicting opinions between family members, friends, and/or medical personnel.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other issues important to me</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Adapted from Your Life, Your Choices®

After you pick your health care agent(s):
• Talk to them about why you want them to be your spokesperson.
• Ask permission to name them as your primary or alternate agent.*
• Discuss your health care wishes, goals and fears with them.
• Give them a copy of your advance directives and any other worksheets you have completed (such as those elsewhere in this book) that outline your wishes.
Sharing Your Thoughts and Decisions

Conversations with those you love and trust are an important foundation for making decisions about your health care. Your choices should be based on your wishes, values, and beliefs. That does not mean that they need to be made alone.

Starting the Conversation

Talk to your family and health care agents* now about your thoughts and plans for your future care. This will help reduce stress if and when they ever need to make decisions for you. It is not always easy to start the conversation, so use whatever approach makes you most comfortable. Some ways to start are:

• Share your reasons for it. Say you don’t want a loved one to make decisions without knowing what you would want.

• Refer to a situation that your family will know, such as the death of a friend or famous person; a sermon; family occasion (baptism, funeral, or wedding); movie; talk show; etc.

• Have a matter-of-fact conversation while preparing legal or business papers. Blame your lawyer, if it helps!

• Share an article with them.

Additional Resources

These websites offer resources to help you have the conversation:

• National Healthcare Decisions Day: www.nhdd.org

• The Conversation Project: www.theconversationproject.org

• CaringInfo, a program of the National Hospice and Palliative Care Organization: www.caringinfo.org

Family Resistance

• Conversations about the end of life are often emotional and difficult for family members.

• When trying to begin a conversation, loved ones may say, “Let’s not talk about dying now. That is a long way off.” You can respond by stating, “I hope that’s true, but I have started thinking about it. I’d like you to know what I want so that you can speak for me if I can’t speak for myself.”

• If you are a child who wants your parents to begin making plans, it may help to express a loving intention for the conversation. You might say, “I want you to know that I care about you very much. Although you may not be ready to talk about this yet, I need to know how I can help you have the care you want if you get really sick. I want to know how you feel about life support and other treatments. Please think about this so that we can talk about it next month if that is okay.”

Remember, this conversation is a process.
Don’t feel like you have to cover everything the first time you talk about it.
Talking with your loved ones about health care decisions can make all the difference. However, you shouldn’t feel rushed to include them before you have an idea of what you might want. What do you need to think about or do before you feel ready to start the conversation?
Talking with your doctor

- It is also important to talk with your doctor now — while you are able to think and communicate clearly — about the kind of care you want at the end of your life. You can talk about current health concerns and/or any health situations you are worried about facing in the future.

- Health care providers are people too, and they might be uncomfortable talking about end-of-life issues. Don't be afraid to ask questions, and to tell your doctor you want to talk openly about the kinds of treatment options that would be available if you became ill.

- Bring this planning guide, along with any advance directives you have completed, to your doctor's appointment. These can help you organize your thoughts and make sure you cover all the important issues.

- When you bring your doctor's office a copy of your advance directives, don't let them get filed away without a conversation. Make sure your doctor knows why you feel the way you do. — Explain your goals and fears about potential health care situations. This will make it easier for your doctor to understand and to follow your wishes.

- Like conversations with your family, talking with your doctor is an ongoing process. Feel free to discuss your advance care plans with any health care provider as you make decisions, come up with new questions, and/or as your health changes.

Suggested questions to ask your doctor:

- Given my current health and family history, am I at risk of any serious health situations that would affect my quality of life?

- Can I count on you to respect my wishes and contact my spokesperson if I am unable to speak for myself?

- What if you are not the health care provider who is there when I need care? How will other providers know about my wishes?

- If you have been diagnosed with a specific illness or condition, or if your health is worsening, be honest about your priorities and fears. Here are some suggested questions for that conversation:
  — What is my diagnosis, and how serious is it?
  — What usually happens in an illness like mine?
  — How long might I live with this illness (a range of time)?
  — What are my options for treatment?
  — What are the benefits and risks of each option?
You can use the next two pages to make notes on your conversation with your doctor and reflect on the planning that you have done so far.
“We bring a deeper commitment to our happiness when we fully understand that our time left is limited and we really need to make it count.”

— Elisabeth Kübler-Ross, MD

*Life Lessons*, 2000
Glossary of Medical & Legal Terms

Below are descriptions of some treatment options. Also described are the legal forms used in advance care planning, as well as common legal terms you may see. Think about the goal of any treatment and talk about it with your family and doctor.

- You might prefer that treatments not be used to prolong your life.
- You might want to try a treatment for a limited period of time, until your condition improves or until doctors decide the treatment is not working. This is called a trial of treatment or time-limited trial.
- You might want to use medical interventions to prolong your life.

• Advance Directive / Advance Health Care Directive:
  Any legal document that allows you to state which life-sustaining treatments you may or may not want if you become seriously ill. Advance directives go into effect only when you cannot communicate or make decisions on your own. These include: Health Care Power of Attorney, Living Will, Do Not Resuscitate orders, and Physician Orders for Scope of Treatment (POST) or Medical Orders for Scope of Treatment (MOST).

• Antibiotics:
  Medications given to cure bacterial infections and reduce discomfort caused by them.

• Artificial Nutrition and Hydration:
  Liquid feedings through a tube in your nose or stomach, or hydration into your vein. These are given when you cannot eat or drink enough on your own. They can be used short-term or long-term, depending on your needs and preferences.

• Blood Transfusions:
  Blood products received through your veins. These are done to replace blood lost during surgery or serious injury. A transfusion can also be done if your body is not making enough blood because of illness.

• Cardiopulmonary Resuscitation (CPR):
  A process used if/when a person’s heart suddenly stops. It tries to keep your blood flowing and restart your heart through strong chest compressions and electricity, if necessary.

• Decision-making Ability / Capacity:
  The ability to make decisions on your own. A person has the right to make his/her own health care choices unless it is determined by a medical professional that he/she cannot understand, communicate, or process information needed to make those decisions.

• Do Not Resuscitate Order (DNR):
  A legal document and medical order that states you do not want resuscitation (which may include CPR, intubation, and ventilation) to be attempted if your heart or breathing stops.

• Financial or Durable Power of Attorney:
  A legal document that names a person you choose to act on your behalf in financial, legal, and business matters. It does not apply to health care situations.
• **Guardian:** A person who is appointed to act and make personal decisions on your behalf if you lose decision-making ability and there is no one else available.

• **Health Care Provider:** Any licensed medical professional who is authorized by the State to provide health care. This includes, but is not limited to: doctors, nurses, nurse practitioners, physician's assistants, and medical social workers.

• **Health Care Agent / Proxy / Surrogate:** A person with the ability and authority to make health care decisions for you, if you become unable to communicate. This could be a relative, an appointed guardian, or the person you named in your Health Care Power of Attorney form (if the legal form is in place).

• **Health Care Power of Attorney:** An advance directive that allows you to name someone to be your health care agent or surrogate. This person will make decisions for you only if you are unable to speak for yourself. **Note:** Health Care Power of Attorney is unrelated to a durable power of attorney.

• **Hospice Care:** Medical care and support for those who have a life expectancy of 6 months or less. Hospice focuses on pain and symptom relief for the person who has a terminal illness. It also provides both patient and family with emotional, social and spiritual support that fits with their wishes.

• **Intubation / Ventilation:** A medical procedure for people who cannot breathe well on their own. Intubation is when a tube is placed through your mouth into your lungs. Ventilation is when air is passed through that tube to breathe for you.

---

**Organ, eye, and tissue donation**

If you wish, you may be able to donate your organs, eyes and tissues for someone else's benefit after your death. Be sure to talk with your family about the decision if this is something you want to do. You can indicate your donation wishes on your advance directives. It is worth noting that organ donation will neither add medical costs nor affect your funeral or memorial plans.

For more detailed information, and to register as an organ donor, visit www.donatelife.net.
• **Kidney (Renal) Dialysis:**
A medical procedure where waste and toxins are filtered out of your blood by a machine. Used when your kidneys are not working well on their own.

• **Life-Sustaining Treatments:**
Medical procedures that use mechanical or artificial means to maintain your bodily functions (for example, breathing and heart beating) when your body cannot do them on its own. These include CPR, intubation, ventilation, artificial nutrition, and more. The focus of such treatments is on prolonging life, rather than lessening pain or discomfort.

• **Living Will:**
An advance directive that allows you to state which life-sustaining treatments you would not want if you are permanently unconscious, or terminally ill and close to death. *Note: Health Care Power of Attorney is not limited to those situations.*

• **Medical Orders for Scope of Treatment (MOST):**
An advance directive available only in North Carolina. Like the DNR, MOST is a medical order designed to ensure your wishes are followed in an emergency situation by any health care provider. It is more comprehensive than a DNR, and states which treatments — including resuscitation, intubation, antibiotics, or feeding tubes — you would or would not want in a medical emergency.

• **Palliative Care:**
Health care and support for those living with advanced illness. It focuses on improving quality of life for the individual and their family, largely through pain and symptom relief for the person who has a terminal illness. Unlike hospice, it can also be combined with curative care.

• **Physician Orders for Scope of Treatment (POST):**
An advance directive available only in South Carolina. Like the DNR, POST is a medical order designed to ensure your wishes are followed in an emergency situation by any health care provider. It is more comprehensive than a DNR, and states which treatments — including resuscitation, intubation, antibiotics, or feeding tubes — you would or would not want in a medical emergency. *Note: POST is currently limited to Greenville and Charleston counties, and not yet available statewide.*

• **Resuscitation / Resuscitative Measures:**
See CPR.

• **Revoke / Revocation:**
To cancel or discontinue your advance health care directive. This is done by destroying your old form(s) or creating a new directive.
## Advance Directives Available
in South Carolina as of 12/2015

<table>
<thead>
<tr>
<th></th>
<th><strong>SC Health Care Power of Attorney (HCPOA)</strong></th>
<th><strong>SC Death with Dignity Act</strong> (SC Living Will or “Declaration of a Desire for a Natural Death”)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited to terminal illness and/or permanent unconscious states?</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Covers a broad range of situations?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Covers what you do and do not want?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Requires witness designated by State Ombudsman if in a hospital or nursing care facility?</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Witness required?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Notary required?</td>
<td>Optional, not required.</td>
<td>Yes</td>
</tr>
<tr>
<td>Is it a physician’s order?</td>
<td>No. It is an advance directive.</td>
<td>No. It is an advance directive.</td>
</tr>
</tbody>
</table>

### Advantages and Limitations

**SC Health Care Power of Attorney (HCPOA)**
- Only invoked when a person is unable to make decisions.
- Most flexible, but if HCPOA & Living Will conflict, Living Will takes precedence.
- Physician must review, consider clinical condition, then issue medical treatment orders.

**SC Death with Dignity Act** (SC Living Will or “Declaration of a Desire for a Natural Death”)
- Cannot be executed in hospital unless witnessed by ombudsman designated by State Ombudsman.
- Physician must review, consider clinical condition, then issue medical treatment orders.
<table>
<thead>
<tr>
<th>Five Wishes</th>
<th>EMS DNR Order</th>
<th>POLST/POST Pilot</th>
<th>If no Advance Directive: Adult Health Care Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Limited to terminal condition.</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Yes. But conditions should be specified.</td>
<td>No. Applies only to EMS personnel.</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Yes</td>
<td>No. Only allows EMS to withhold or withdraw resuscitative measures.</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
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<tr>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>No</td>
<td>Yes. Physician must sign.</td>
<td>Yes. Physician must sign.</td>
<td>No</td>
</tr>
</tbody>
</table>

- **Costs**
  - $5 per form for one.
  - $1 per copy for orders of 25 or more.
  - 12 pages long.
- **Physician**
  - Must review, consider clinical condition, then issue medical treatment orders.
  - It is not a legal document as defined by state law. However, if notarized and witnessed, it meets the legal requirement as an advance directive in SC.
- **Applications**
  - Only when a patient is experiencing cardiac arrest.
  - Very limited.
  - Applies only when patient is under the care of EMS personnel.
  - Since it is a physician's order, it can be followed.
- **Also signed by patient**
  - Giving healthcare workers actual knowledge of patient's wishes.
  - Very flexible and since it is a physician's order it can be followed right away.
  - Charleston & Greenville counties are currently piloting POST, and it should be available statewide by 2017.
- **Priority of proxy**
  - Decision maker set by statute and may be unclear.
  - Physician should locate proxy, discuss with proxy, consider clinical condition, and then issue orders. If there is no proxy or if no proxy is available, the physician can issue medical orders in keeping with the Act.
# Advance Directives Available in North Carolina as of 12/2015

<table>
<thead>
<tr>
<th></th>
<th>NC Health Care Power of Attorney (HCPOA)</th>
<th>NC Advance Directive for a Natural Death (“Living Will”)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Limited to terminal illness and/or permanent unconscious states?</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Covers a broad range of situations?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Covers what you do and do not want?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Witnesses required?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Notary required?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Is it a physician’s order?</td>
<td>No. It is an advance directive.</td>
<td>No. It is an advance directive.</td>
</tr>
</tbody>
</table>
| Advantages and Limitations                  | • Only invoked when a person is unable to make decisions.  
• Physician must review, consider clinical conditions, and then issue medical treatment orders. | • Only invoked when a person is unable to make decisions. 
• Two physicians must review, consider clinical conditions, then issue medical treatment orders. |
<table>
<thead>
<tr>
<th>Five Wishes</th>
<th>DNR Order</th>
<th>NC Medical Orders for Scope of Treatment (MOST)</th>
<th>If no Advance Directive: Informed Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td>Limited to cardiac arrest.</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Yes. But conditions should be specified.</td>
<td>No. Only allows EMS to withhold or withdraw resuscitative measures.</td>
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<td>No</td>
<td>Yes. Physician must sign.</td>
<td>Yes. Physician must sign.</td>
<td>No</td>
</tr>
</tbody>
</table>

- Costs $5 per form. $1 per copy for orders of 25 or more.
- 12 pages long.
- Physician must review, consider clinical condition, then issue medical treatment orders.
- It is not a legal document as defined by state law. However, if notarized and witnessed, it meets the legal requirement as an advance directive in NC.
- Applies only when a patient is experiencing cardiac arrest.
- Since it is a physician order, it can be followed by EMS.
- The form is available through a health care provider.
- Must be reviewed if the patient's treatment preferences change. Review is recommended when the patient is admitted and/or discharged from a health care facility; or when there is a substantial change in the patient's health status.
- Priority of proxy decision maker set by statute and is often unclear.
- Physician should locate proxy, discuss with proxy, consider clinical condition, and then issue orders.
Outlining Your Plans

“The time to repair the roof is when the sun is shining.”
— John F. Kennedy
State of the Union Address, January 1962

Advance health care directives* are legal documents that help you state your preferences for future care. When completed, these forms will be a guide for your doctors and loved ones if you are ever unable to communicate what you want.

Remember, these plans can be updated and rewritten as many times as you need or want. You can always change your mind, make edits, or revoke* your directives if they no longer fit your health care needs. If you do make edits, be sure to initial the changes and give updated copies to anyone that had the previous version. If you revoke an old directive to make a new one, destroy the old copies and again be sure to give out the updated version.

The questions below may help you summarize your wishes for care. They can be attached to an advance directive and/or put into your medical record, but these pages are not a legal document. Remember, no one will know your wishes unless you tell them!

1. If I were unable to make health care decisions for myself, I would want these people to communicate for me:

1) _________________________  2) _________________________  3) _________________________

2. If I found out I was going to die soon, what things would I want to take care of first?
   For example, deal with a business or financial concern, handle a legal matter, mend a relationship, etc.

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
3. If I were dying, the selected treatment options below sound best to me. (Feel free to choose more than one.)

- My main wish would be for care that allows me to be comfortable, peaceful, and free from pain. This includes palliative* and hospice care*, if possible.

- I would want to go to the hospital for treatment if needed for comfort, but I would not want to be connected to life support machines.

- If it were unclear whether a specific treatment (such as artificial nutrition* or being on a ventilator*) would improve my chances of living, I would like to have a time-limited trial* of this treatment in the hospital. If I do not improve, when would this treatment trial become unacceptable to me?

- My main wish is to live as long as possible, even if that means receiving uncomfortable life sustaining treatments*.

- I would want to go to the hospital for treatment that might help me in any way, comfort or otherwise.

- Other: __________________________________________________________

- Other: __________________________________________________________

4. If I were dying and became unable to eat, I would want:

- To have a feeding tube* inserted into my stomach, nose, or mouth.

- To have a feeding tube for a limited period of time. If I do not improve, when would this treatment become unacceptable to me?

- To not have a feeding tube inserted.

5. I want to be an organ, eye, and/or tissue donor.

- Yes  □  No

6. If necessary for organ donation, I would like life support treatment.

- Yes  □  No
Outlining Your Plans … continued

Advance health care directives to consider completing at different stages of life — and to discuss with your doctor — include

- Health Care Power of Attorney*
- Living Will*
- Five Wishes*
- Physician/Medical Orders for Scope of Treatment (POST/MOST)*
- DNR*

Health Care Power of Attorney and Living Will forms are state-specific. You can get them for free from your doctor, hospital, local hospice organization, or a lawyer. You can also download these forms from:

South Carolina Advance Directives: www.aging.sc.gov/legal/Pages/default.aspx
North Carolina Advance Directives: www.secretary.state.nc.us/ahcdr/Forms.aspx

Five Wishes meets state requirements to be an advance directive. However, its contents are not written into state law, as other advance directives are. Therefore most lawyers recommend legal forms like the Healthcare Power of Attorney over Five Wishes, but you may still find Five Wishes helpful in your planning process. You can purchase the Five Wishes document (online or in print) from www.agingwithdignity.

Physician/Medical Orders for Scope of Treatment (POST/MOST) and DNR forms can only be obtained from your doctor, hospital, or local hospice organization. This is because, unlike the other advance directives, they are actual physician’s orders. See the comparison charts on pages 20-23 for details.

Additional resources about many aspects of advance care planning and completing advance directives can be found on The Carolinas Center’s website at www.cchospice.org/iitwt
Next Steps

TO-DO Checklist

☐ Begin the conversation with key family members and loved ones.

☐ Obtain and complete appropriate health care documents.

☐ Keep the original copies of your advance directives and this planning guide where they can easily be found.

☐ Give your chosen proxy* (or proxies) a copy of the advance directives plus any worksheets or notes you’ve made about your wishes. Make sure they know where to find the original documents.

☐ Give your doctor a copy of your directive and make sure it is put in your medical record. Talk through your wishes and make sure your doctor will support them if the time comes.

☐ Set a date to have additional conversations and share copies of your documents with:

  Family ________________________________
  Friends ________________________________
  Attorney ________________________________
  Spiritual Advisor(s) ________________________________
  Others ________________________________

☐ Fill out the advance directive card inside the back cover of this guide, cut it out and put it in your wallet so you can always have it with you.

☐ Continue the conversation. Set a date each year to review your advance directive forms. Consider using National Healthcare Decisions Day, which is April 16 every year.

  Date: _______________

It's also good to review your advance directives if you experience any of “the three D's”

1) **Divorce**: when you experience any major family change such as a divorce.

2) **Diagnoses**: when you are diagnosed with a serious health condition.

3) **Decline**: when you experience a significant decline in health.

Reflection

Congratulations! You have educated yourself about the process of advance care planning and its importance. You have started thinking about what matters to you and about the choices you might face. You have communicated and documented these choices.

Isn't it freeing to know that if something were to happen, your plan is ready to implement. This peace of mind is a gift for yourself and your loved ones.

Now, just enjoy life! Share this gift of conversation with others, and encourage them to realize that **now is the time to talk.**
Sources


Acknowledgements

The Carolinas Center gratefully acknowledges the contributions of staff and volunteers in revising the first edition of *Isn’t It Time We Talk?* Tremendous thanks to TCC Special Projects Intern Maggie Oliver who spearheaded this revision process. With thanks also to Wilma Rice, MSN, RN, CEN, Education Specialist with Roper St. Francis Professional Development; Karen Reeves, Vice President of Risk Management and Accreditation at the South Carolina Hospital Association; and Shannon Pointer, MSN, RN, Community Educator at Hospice and Palliative Care Center of Alamance-Caswell for their valuable contributions.
I have Advance Directives

MY NAME

ADDRESS

PHONE

EMAIL

Copies have been given to:

NAME

RELATIONSHIP

PHONE

EMAIL

Physician

NAME

PHONE

EMAIL

IN CASE OF EMERGENCY

My health care agents:

PRIMARY AGENT NAME

PHONE

EMAIL

ALTERNATE AGENT NAME

PHONE

EMAIL

DATE

Provided by:
The Carolinas Center – 800.662.8859