BEGINTHE CONVERSATION • ORG

It's Time to FACE the ELEPHANT IN THE ROOM

7 STEP WORKBOOK FOR ADVANCE CARE PLANNING

First Edition



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Begin the Conversation is a public education program created by Lower Cape Fear Hospice in Wilmington, N.C. to motivate people to begin the conversation about advance care planning as well as to complete documentation to support their choices.

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Introduction

In our busy world, we rarely have quiet moments to reflect on our hearts' desires. When we do, we don't want to think about death, especially our own. We often ignore the possibility of death until a crisis occurs and we see those we love most experience pain, sickness, injury or trauma.

This workbook has been created to help you think about what you would want if you were sick (very sick) or injured (very injured) and could not communicate with those around you. Some of these questions will be hard to reflect upon, but avoiding these discussions does not guarantee an escape from death. The only promise life provides us is that each of us will one day face death. This workbook is an opportunity for you to discover how you want your final months, final days and final hours lived. It can become a great swan song, if you embrace it.

What is BeginTheConversation.org?

BeginTheConversation.org is a public education program created by Lower Cape Fear Hospice (LCFH) in Wilmington, N.C. It is designed to encourage everyone to identify and communicate their advance care planning choices.

As a hospice organization for more than three decades, LCFH discovered many people in hospice care had not completed advance care documents. Few had begun a conversation about end-of life choices. To change that, LCFH created Begin the Conversation to engage everyone, even those not yet facing end of life (EOL). The goal is for everyone to begin this important conversation long before a crisis occurs.

A study from the Johns Hopkins Bloomberg School of Public Health found two-thirds of respondents did not have advance directives nor were they comfortable having critical end-of-life conversations. However, most people had preferences about the kind of medical care they wanted if faced with end-of-life decisions. There are great benefits of advance care planning and communicating your healthcare choices. Not only is it important for you to express your choices, it is a gift for your family.

Aggressive end-of-life care can worsen your quality of life and can negatively affect your family's bereavement. A 2013 study published in the Journal of the American Medical Association shows a person without advance care planning can be physically moved three times in the last weeks of life. That's why Begin the Conversation encourages you to plan for these situations long before a crisis occurs. It can help you to avoid unnecessary treatments as well as fragmented care.

According to a Dartmouth Study, cancer patients see 10 or more doctors during the last six months of life, which puts a strain on them and increases chances of fragmented care. Most Americans do not want aggressive, end-of-life, hospital-based treatments. We prefer to die at home – as comfortable as possible – surrounded by family and friends.

If that is the case, why are 60% of all Americans dying in hospitals?

Begin the Conversation is a tool to assist you in figuring out what you want if something happens to you, but most importantly it can help prepare friends and family by having the conversation about what you would want if something happens, whether that's a tragic accident or old age or illness.

It's time to face the elephant in the room.



Begin

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"This is something my wife and I both need to do."

I was able to relate to the "real stories" and the presentation also helped me see this as a way to help others. I appreciated the different perspectives on the issues, and this was a great opportunity to learn about preparing for my next phase of life. - Community Member

"We will begin the conversation."

What a great service to the community. This workshop has provided me with a new perspective and appreciation on hospice care and its purpose. My family and I will definitely Begin The Conversation... - Community Member

"Excellent program!"

I really appreciate these conferences. The new information from the doctor's and patient's perspective and connecting with others who are going through this process has been so helpful for me. It really creates a nice circle to help all of us grow, give and do better! - Family Member

"I will be spreading the word to others."

"Thank you!" "Thank you!" Your speakers were very knowledgeable and compassionate and have given me the motivation I need to help me through this important process with my family. - Family Member "Very much worth my time!"

BEGIN

At any time in your life, you may be unable to communicate your healthcare choices because of an injury or serious illness. Having a plan will make it easier for you, your doctor and your loved ones to ensure your wishes are honored.

The first step in the advance care planning process is to learn as much as you can about it. This will increase your knowledge about healthcare choices and the importance of planning, and will also encourage communication with loved ones, caregivers, and healthcare professionals so everyone can share in that knowledge.

SO LET'S START FROM THE BEGINNING:

Ignorance is the curse of God; knowledge is the wing wherewith we fly to heaven.

- William Shakespeare

What... is advance care planning?

Advance care planning is a process that enables you to plan your future healthcare. It provides direction to healthcare professionals when you are not able to make and/or communicate your own healthcare choices. Advance care planning is appropriate for adults at all stages of life, and can help reduce your stress and anxiety while improving your end-of-life care.

P Why... is advance care planning important?

Advance care planning helps ensure your healthcare wishes when you are unable to communicate your wishes.

Wish: Nearly 80% of people say they would prefer to die at home. Fact: Almost 75% of people don't die at home.

Fact: People without advance care planning are moved an average of three times in the last few weeks of life.

Fact: Having a living will is associated with decreased likelihood of dying in a hospital.

Fact: Less than one third of American adults have advance directives expressing their wishes.

Wish: About 80% of people say they don't want their life extended by machines. **Fact:** The use of mechanical ventilation in the 90 days prior to death has increased in the last 15 years. Who...should do advance care planning?

Because you never know when a serious illness or injury could occur, advance care planning should be practiced by all adults who are 18 years old and older. Four high-profile stories about end-of-life centered around Brittany Maynard, Terri Schiavo, Nancy Cruzan, and Karen Ann Quinlan, all of whom were young women in their 20's and 30's.

Advance care planning is important to complete if you: (Mark all below that are true)

- _____ Have specific or unique healthcare preferences
- _____ Want to provide peace of mind to family members
- _____ Like to have a say in your healthcare decisions
- _____ Want to live well, even through your own death
- _____ Are living with serious, advanced illness
- _____ Are living with chronic illness, either potential or realized

If you said yes to any of the responses above, now is the time to begin the conversation about your end-of-life wishes.

When...is advance care planning important?

Advance care planning is important throughout your entire life, including (but not limited to):

- Around major events like graduation, marriage, relocation, etc.
- Before major events such as vacations, hospital visits, etc.
- When life changes having children, death of loved ones, etc.
- When your mind changes
- When you are 18 or older

Remember, it is vitally important for you to do advance care planning before a crisis occurs. This will help remove some of the stress that happens when decisions have to be made and communicated.

How...do I begin?

Begin by learning more about the importance of advance care planning. By using this workbook, you've already begun the process. Yay for you! Keep looking for additional information and resources and when you are ready, then move on to the next step... prepare.



Reflective Thoughts

- Learn from others.
- This is not a time to evoke action. It's a time to pause, reflect and listen to your voice.
- After seeing the research and stats, how does this make you feel?
- Think about a loved one you have lost. Would you want your end-of-life to be similar or are there things you want to be different?

EDUCATE

PROVEN FACTS TO MOTIVATE ACTION...

 Senior care professionals surveyed say 70% of family conversations about aging are prompted by an event such as a health crisis or other emergency.

* Home Instead Senior Care, U.S. Research Report, 40/70 Rule

- Most people say they prefer to die at home, yet only about one-third of adults have an advance directive expressing their end-of-life care wishes. Among those 60 and older, only about half have completed an advance directive.
 * Pew, 2006; AARP, 2008
- Only 28% of home healthcare patients, 65% of nursing home residents and 88% of hospice patients have an advance directive on record.
 * Jones, 2011
- 65-76% of doctors whose patients had an advance directive were not aware it existed.
 * Kass-Bartelmes, 2003
- Even among severely or terminally ill patients, fewer than **50%** had an advance directive in their medical record.
 - * Kass-Bartelmes, 2003
- **82%** of estate-planning attorneys surveyed recommended having discussion about aging and end-of-life issues before an adult child is 40 and before a parent is 70. ** Home Instead Senior Care, U.S. Research Report, 40/70 Rule*
- 34% of American adults are estimated to be conversation avoiders. That means they
 haven't talked about any important end-of-life issues with their parents or children, or
 they have only talked about one issue.
 ** Marist Poll*

- Most Americans (71%) believe it is more important to enhance quality of life for seriously ill patients – even if it means a shorter life – than to extend the life of seriously ill patients through every medical intervention possible.
 * Regence, 2011
- **66%** of family disputes about aging or end-of-life issues that end up in court could have been avoided if a family had clearly discussed and documented wishes in advance.

* Home Instead Senior Care, U.S. Research Report, 40/70 Rule

- There's a big gap between what people say they want and what actually happens:
 60% say that making sure their family is not burdened by tough decisions is
 "extremely important," yet 56% have not communicated their end-of-life wishes.
 * Survey of Californians by the California HealthCare Foundation, 2012
- 70% of people say they prefer to die at home, but 70% die in a hospital, nursing home, or long-term care facility.
 * Centers for Disease Control, 2005
- 80% of people say if they were seriously ill, they would want to talk to their doctor about end-of-life care, but only 7% report having this important conversation. * California HealthCare Foundation, 2012

82% of people say it's important to put their wishes in writing, but only 23% have actually done it.
 Colifernia HealthCare Soundation 2012

* California HealthCare Foundation, 2012

What do these facts teach you/show you/tell you?



IT IS BETTER TO PREPARE 10 YEARS TOO EARLY THAN ONE DAY TOO LATE.

Key things to remember as you prepare:

- Begin by acknowledging this is a process. It's not something to accomplish quickly.
- Begin by knowing your loved ones might disagree with you, and that's okay.
- Begin by acknowledging you will not be able to figure out every possible scenario. Keep to basics and generalities.
- Begin by thinking about your own beliefs, philosophies, values, and preferences today and consider the future. Write those decisions down and add to them.
- Begin by including loved ones in the planning and in conversations as soon as you are ready. There is no rush. The key is to know your own wishes first.
- Begin by recalling end-of-life experiences with loved ones. Use personal memories to set the foundation for your own choices.
- Begin by understanding it is never too soon to begin this process.
- Begin by thinking about the things you do and you don't want at end of life.

Nectar List

What are you most proud of? List things you've accomplished so far:

Bucket List

List at least five things on your bucket list:

What Would You Do?

On your way home from the grocery store, your vehicle is hit by a large truck that ran a stop sign. Emergency personnel are called and they work heroically to keep you alive and get you to the hospital. Once at the hospital, you are in surgery for hours while medical staff deals with your life-threatening injuries. Unfortunately, they cannot repair the damage. They decide to stabilize you on machines until your family and/or loved ones arrive at the hospital. When they get there, the doctors deliver the bad news.

What do you want them to do?

You have lived to become 94 years old! While your body has handled the aging process remarkably well, your brain has not. Doctors diagnosed you with dementia and the disease has made normal, everyday activities extremely challenging for you and your caregivers. Doctors can't tell you and your family exactly how much time you have left, but you know the disease will not stop progressing. Life is only going to get more difficult. Your loved ones decide to have a meeting to discuss a plan for your care. They know a crisis is right around the corner.

What do you want them to do?

You and your spouse had a wonderful 15 years of marriage before a tragic accident took his/her life. While you were together, you talked about everything...your hopes and dreams, daily frustrations and your life together. You even talked about your end-of-life preferences. You know your spouse wanted to be cremated with his/her ashes spread in the exact location where you met. You still remember that conversation, how you both were laughing, but never really anticipating you'd need to do it. Now, it's real. Unfortunately, your spouse's parents and siblings have told you, in no uncertain terms, their family does not believe in cremation and they will have a traditional funeral and burial ceremony at their church cemetery. You want to honor your spouse's wishes, but you also respect his/ her family's traditions.

What do you do?

Your 87-year-old grandmother is in the hospital. Her health has been declining for some time, with several trips to the emergency room. This most recent episode has you worried it could be the last. The doctor tells you, with the most compassion possible, your grandmother is comfortable and stabilized for the moment, but it is highly unlikely she will ever come off the ventilator. You want to confirm the seriousness of her condition, so you ask the doctor to explain her chances. Trying to give you the information you are looking for, the doctor says your grandmother has about a 10% chance of coming off the machines and her quality of life would be compromised. You discuss the fact that your grandmother has a Living Will and she has said she does not want to live like that. You are your grandmother's designated Healthcare Power of Attorney, so the decision is in your hands.

What do you do?

Your 39-year-old son is in the hospital. He has a rare disease that has progressed so quickly it is now threatening his life. The doctor tells you he is comfortable and stabilized for the moment, but it is highly unlikely he will ever come off the ventilator. You want to confirm the seriousness of his condition, so you ask the doctor to explain his chances. The doctor tells you he has a 10% chance of coming off the machines and his quality of life will be compromised. You tell the doctor that your son, who also has three small children of his own, has a Living Will. You are your son's designated Healthcare Power of Attorney, so the decision is in your hands.

What do you do?

You just found out you only have a year left to live. Take a moment and reflect on your life.

What would you change about how you live your life?

What makes life worth living for you?

If you could control three things about your own death, what would they be?

What's Important to You?

If you were faced with a life-limiting illness or injury, rank the importance of the following situations:

- **3 = Critically important**
- 2 = Important
- 1 = Only slightly important
- 0 = Either not important at all or I feel the opposite
- I do not want to be a financial burden to my family.
- I want to spend my final days/weeks/months at home.
- I want to be completely free of pain.
- I want to receive hospice services as soon as it's possible.
- I want to be surrounded by family and friends.
- I want people to speak to me freely about my condition.
- I want my loved ones to be at peace.
- I want to maintain a certain level of quality in my life.
- I want the chance to share my life story with others.
- I want to keep connected to my faith and/or faith community.
- I want to have all my affairs in order (healthcare, financial, legal, etc.).
- I want to be remembered as: _____

I want to say: _____

Medical Decisions

Time is limited. If you were facing the **last year** of your life, how would you answer these questions:

1. If you had no pulse and were not breathing, you would recommend:

		Attempt resuscitation (CPR)
		Why?
		DO NOT attempt resuscitation (DNR/no CPR)
		Why?
		Depends
		Explain:
		Not ready to answer this question
2.		ou were in the last six months of your life, still had a pulse and were breathing could not speak for yourself, what would you recommend?
		Full scope of treatment: Use intubation, advanced airway interventions, mechanical ventilation, cardioversions as indicated, medical treatment, IV fluids, etc.; also provide comfort measures. Transfer to hospital if indicated.
		Limited additional interventions: Use medical treatment, IV fluids and cardiac monitoring as indicated. <i>Do not use intubation or mechanical ventilation</i> ; also provide comfort measures. Transfer to hospital if indicated. Avoid intensive care.
		Comfort measures: Keep clean, warm and dry. Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. <i>Do not transfer to hospital unless comfort needs cannot be met in current location.</i>
3.	lf yc	ou were in the last six months of your life, you would want:
		Antibiotics, if life can be prolonged
		Determine use or limitations of antibiotics when infection occurs
		No antibiotics. Use of other measures to relieve symptoms.

4. If you were in the last **six months** of your life, how would you want to deal with medically administered fluids and nutrition?

	Offer oral <u>artificial nurtition and hydration</u> if physically feasible <u>IV fluids</u> long-term if indicated IV fluids for a defined trial period	For reference see glossary on page 36.
	No IV fluids. Provide other measures to ensure comfort Feeding tube, long-term if indicated	Y
	Feeding tube for a defined trial period	
	No feeding tube	
Why		

5. If you were injured or had a serious illness, would you want life-sustaining treatments? How long would you want to continue with this treatment?

* Reference: NC MOST	(Medical C	Orders for Scope	of Treatment)
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Location

If you could, you would like to die:

At home with loved ones around

- At home with community services, such as palliative care/hospice care or other end-of-life options
- Hospital with loved ones around me
- Nursing home with loved around me
- At a hospice care center where my needs can be addressed
- Other options you desire:

Pain Management Choices

If you were faced with end of life:



I would want pain management to include all drugs to keep me from being in pain.

I would want pain management as long as I could remain aware of my surroundings and communicate with my loved ones.

I would want pain management, but I would like to exclude the following drugs:

I'm not interested in pain management.

I do not know enough about this topic. I will speak to my doctors about pain management.

Personal Care

When you are in the last few months of life and are no longer able to maintain your own self-care, your desires are:

Bathing:

Grooming:

Other personal care options: _____

Pet Care

Number of pets _____.

Names and type of pets:

Remember, you provide your pet with water, food, shelter, veterinary care, and love and companionship. Plan ahead to ensure your beloved pet will continue to receive this care should something happen to you.

If you are unable to care for your pet, your wishes are:

	will be cared for by	
Pet Name	,	Person or Agency Name
	will be cared for by	
Pet Name	, , , , , , , , , , , , , , , , , , ,	Person or Agency Name
	will be cared for by	
Pet Name		Person or Agency Name
	will be cared for by	
Pet Name		Person or Agency Name
	will be cared for by	
Pet Name		Person or Agency Name
Does your pet have special needs (allergies, health condition	s, preferred food etc.)?
		, protonioù 100ù 0toi)!
Matters of the Heart		
When your are in the last few day	/s of your life, your d	lesires are:
I want these people at my bedside:		
r want these people at my bedside.	·	
I DO DO NOT want someo	one praying at my bed	side. If yes, who?
		, , <u> </u>
I DO DO NOT want my fav	orite TV show on. It is	3
I DO DO NOT want fresh fl	owers every day.	

Do you want your favorite music playing? If yes, list your favorite music or songs:

Do you want someone to hold your hand? If yes, who do you want it to be? _____

Is there someone you would like ask forgiveness from or provide forgiveness to? If yes, who is it and how do you plan to address this?

Recommendation: Don't wait to forgive someone or ask forgiveness. Have courage to move forward before you face end of life. You might heal a wound that does not need to wait until death.

Going to the Chapel

Some people say they would like to have a funeral before they die. They like the idea of having a celebration of life to see and interact with friends, family and others. They see it as a way to embrace the reality that time together is limited. Others prefer a more traditional funeral, while some may want no funeral or memorial service at all.

Do you want to be buried? Where? Do you have a funeral plan?	Remember, this is your call. Don't you love that your voice is heard after your death? Having the final say may or may not be important to you, but it is important to express your desires and wishes.

Do you want to be cremated? Where do you want your ashes spread or do you want someone to hold onto them or bury your ashes?

Memorial Service/Celebration of Life Ceremony

Funeral/service location:
Scripture/other messaging:
Music:
Which photo do you want used?
I want
to speak at my funeral or memorial service/celebration of life ceremony.
I want a published obituary.
Additional thoughts for your memorial service/celebration of life.

Writing Your Obituary

Include your full name, date and place of birth, immediate family living and deceased, professional accomplishments, affiliations and other information you would like included in your obituary.



Prepare a list of people with whom you want to communicate your end-of-life choices. Note: This is not asking who you think will be the easiest to talk to or the most convenient. Instead, think about who will need to know your wishes and may play a part in your end-of-life journey.

Family Members

(Spouse, children, parents, siblings, grandparents, grandchildren, etc.):

Other People (Friends, neighbors, church members, caregivers, personal friends, etc.):

Professionals (Doctors, clergy, attorneys, etc.):

Tips to Begin the Conversation

Now that you have created a list of people to communicate your healthcare choices to, here are some strategies to help make it happen:

Model the Way: If you want to discuss someone else's choices (i.e. a parent) be willing to do the work yourself first. Think about your own preferences. Put your decisions in writing. Then, open the conversation by sharing your own thoughts, rather than putting the other person on the spot. It's only fair.

Set the Stage: This conversation can be exceptionally difficult if other people are not prepared for it. It does not mean they have to complete this entire workbook, but it can be helpful if they know the conversation is coming. Also, use your knowledge of the people involved; some will prefer group interactions but others might like it to be more one-on-one.

Use a Reference Point: It can be useful to find a trigger event to begin the conversation, such as the death of another person, a relevant news event, a book/article/TV episode, etc. Begin by asking what the other person thought about it and see if this can lead into deeper conversations. Remember, take small steps at first.

Don't Rush: This conversation is a process. You can revisit it more than once. Don't feel like you have to cover it all the first time you talk about it. Some family and friends will need more time to be fully receptive to the conversation.

Use Two-Way Communication: Allow your loved ones to share their own beliefs/choices/ preferences and use them as a point of comparison or contrast to your own. Understand you don't have to be in agreement to begin this conversation. Try to create a win-win scenario where you are able to express yourself and your loved ones feel empowered to do the same. Remember to listen as much as you talk.

Remember the Purpose: Advance care planning has two goals: to make sure your healthcare wishes are expressed and honored, and to give a gift to your family and loved ones. It provides them with critical information and confidence needed for future decisions.

Break the Ice:

"I've recently completed my advance care planning documents and wanted to share them with you so you would know what I want."

"If anything were to happen to me, I don't want you to stress over what to do for me and my healthcare so I've written a few things down."

"Did you see that episode of 'Grey's Anatomy' last night? What did you think about that family's decision?"

Conversation Tools: Discuss tools from the Prepare section of this workbook with your loved ones

- What Would You Do?- Pages 5-8
- What's Important to You Page 9
- In the Know Worksheet Pages 22-32



Reflective Thoughts

• Communicate your wishes. If a medical emergency happens, at the time of a crisis your loved ones will hear your voice and become your advocates.

The single biggest problem in communication is the illusion that it has taken place. - George Bernard Shaw

- Without communication advance-care documents can be confusing and may leave your advocates confused and in shock.
- This does not have to be a serious conversation. It can be light-hearted and humorous. Don't make a simple process complicated.
- When you communicate your wishes, you may realize you need to rethink who you chose for your Healthcare Power of Attorney. Your Healthcare Power of Attorney needs to be able to carry through on your directives. Some friends and family just can't do that.

5 DOCUMENT

There are two key healthcare documents that assist in advance care planning – a Living Will and a Healthcare Power of Attorney form.

A Living Will is a document where you specify your future medical treatments in case of incapacity, usually at the end of life, or if you become permanently unconscious, in a persistent vegetative state, or beyond reasonable hope of recovery.

A **Healthcare Power of Attorney** form is a document where you appoint a healthcare agent to make future medical decisions if you are incapacitated. This agent will speak on your behalf based on your stated wishes and/or assessment of your best interests.

Healthcare Power of Attorney and Living Will (*North Carolina example)

- Legal document
- No cost to create, unless attorney or notary charges for services
- Every state has unique documents, but are generally accepted in other states
- Person needs capacity to originally execute the document, but only goes into effect when the person loses capacity or ability to communicate
- Notary, witnesses, and signature of person to make legal (does not require attorney)
- Photocopies may be honored
- Does not expire

For more information about advance care planning documents and to find forms and resources for your state, visit www.BeginTheConversation.org/resources.

The Chosen Few

• If you could not speak, who do you want to speak for you? List three people to serve as your healthcare agent who would uphold your end-of-life wishes if you could not communicate them yourself. If you don't have three, that's okay.

• Why do you think these three people would advocate your wishes?

List Your Chosen Few

(This section is to help prepare you to complete a legal Healthcare Power of Attorney form. This is not a legal document.)

Nam	e:
Cont	act information:
	I have had the conversation with this person and told him/her about my wishes and that I have selected him/her.
	I have not had the conversation with this person, but plan on doing it on
	e:
Cont	act information:
	I have had the conversation with this person and told him/her about my wishes and that I have selected him/her.
	I have not had the conversation with this person, but plan on doing it on
Nam	e:
	act information:
	I have had the conversation with this person and told him/her about my wishes and that I have selected him/her.
	I have not had the conversation with this person, but plan on doing it on
You	must list your healthcare agents in the order of preference. For example, if you have echildren, you need to put them in order of preference to serve as your healthcare agent.

three children, you need to put them in order of preference to serve as your healthcare agent. Remember, to have multiple people agree on the same thing is rare. This is why it's important to have the conversation with all of your healthcare agents. It's up to you to share your voice and wishes. Now you're ready to fill out the Healthcare Power Attorney Form. You can find forms and resources for your state at www.BeginTheConversation.org/resources.

Many states also have advance care planning documents that encourage conversations and decisions between patients, loved ones, and healthcare providers. One such document is called a Medical Orders for Scope of Treatment (MOST) form. It may also so be referred to as a Physician Orders for Life-Sustaining Treatment (POLST) form.

The **MOST form** is a doctor's order that helps express your healthcare preferences at end of life. It includes several decisions including resuscitation status (similar to a DNR), as well as wishes about intubation, antibiotic use and feeding tubes. You should have legal advance directives, such as a Living Will and Healthcare Power of Attorney form, that identify and inform others to make healthcare choices on your behalf when you are unable to communicate for yourself. However, as a medical order primarily for people with serious illness, the MOST document directs your care. The MOST form can provide critical direction that the Living Will and Healthcare Power of Attorney cannot because they are not medical orders.

MOST/POST/MOLST/POLST

- Medical document
- Signed by healthcare provider and you or your representative
- Does not require notarization or witnesses
- You can void this document at any time
- Addresses CPR status and be used in traumatic situations
- Endorsed POLST States (includes mature states):
 - California
- Louisiana - Montana
- Colorado
- New York
- Georgia
- Hawaii - Idaho

- North Carolina
- Oregon

- Pennsylvania
- Tennessee
- Utah
- Washington
- West Virginia

Other Documents

There are other healthcare-related documents that can be a part of the conversation, including (but not limited to):

- Organ, eye, and tissue donation registration
- Donation of remains for research arrangements
- HIPAA release form
- Healthcare-related insurance coverages
- Funeral, memorial service, burial/cremation planning



Reflective Thoughts

- Advance care documents can be boring but they are necessary. Without these documents to support your conversation, your wishes are less likely to be honored. Your advance care documents are only as effective as the conversations you have about them.
- Healthcare documentation is different (and separate from) legal and financial planning documentation. A Living Will is not a Last Will and Testament. A Healthcare Power of Attorney form is not a Financial Power of Attorney form.
- Attorneys are not required to execute these documents, but you are encouraged to seek legal counsel if you have any questions.



Effective Date:

In the Know was created to help you outline where your most important documents are stored, as well as key pieces of information your family and friends may need after your death. This is not a legal document like the MOST/POST/MOLST/POLST, Healthcare Power of Attorney or Living Will forms, but is a tool to help provide your loved ones with information they may need after you're gone. In the Know can help your family feel like those overwhelming and insurmountable tasks are manageable. You can help those you love by completing this section. It's a gift for your family and friends.

Assets

Financial Advisor
Name:
Address:
Telephone:
Attorney
Name:
Address:
Telephone:
Insurance Agent
Name:
Address:
Telephone:
Pension Benefits
Name:
Address:
Telephone:
Employer
Name:
Address:
Telephone:

Accountant	
Name:	
Address:	
Telephone:	
Mortgage Holder	
Name:	
Address:	
Telephone:	
Other	
Name:	
Advisors Here is a list of my investments, including pl and telephone number for each item, as we	
Here is a list of my investments, including p and telephone number for each item, as we	
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Deposits

I have made deposits on certain accounts. The accounts are:

Institute holding deposit:	:
Amount:	
Phone:	
Documents are located:	

Liabilities

Here is a list of my liabilities, including a contact name and phone number of each, as well as the location of any related documents:

Liability:
Contact:
Phone:
Documents are located:
Liability:
Liability:
Contact:
Phone:
Documents are located:
Liability:
Contact:
Phone:
Documents are located:
Liability:
Contact:
Phone:
Documents are located:
Liability:
Contact:
Phone:
Documents are located:
Liability:
Contact:
Phone:
Documents are located:

25

I have the following life insurance policies (including company-owned):					
Туре	Owner	Beneficiary	Face Amount	Existing Loans	Cash Value
			\$	\$	\$
			\$	\$	\$
			\$	\$	\$
			\$	\$	\$
			\$	\$	\$
			\$	\$	\$

Policies can be found at: _____

I have the following disability insurance	policies:
Company	Policy Located At

I have the following long-term care insurance policies:		
Company	Policy Located At	

I have the following health insurance policies:		
Company	Policy Located At	

I have the following other policies:		
Туре	Company	Policy Located At
Auto		
Umbrella		
Home		
Other		
Other		

If I become disabled, please make sure to pay the premiums on the policies, which will provide me or my family benefits.

If I am disabled, my life insurance policy

Allows Does Not Allow for pre-payment of death benefits to support me.

If I am disabled, my life insurance policy

Allows Does Not Allow you to stop making premium payments.

If I am disabled, my disability insurance policy

Allows Does Not Allow for pre-payment of death benefits to support me.

Employment

I have the following disability and/or death benefits where I work or worked (describe):

Retirement Plan(s):
Life Insurance:
Health Insurance:
Long-Term Care:
Disability Insurance:
Deferred Compensation:
Stock Ownership:
Stock Options:
Cafeteria Plan:
Other:

I have executed each of the fo		Location Stored
Document	Date Signed	Location Stored
Will		
Living Will		
Healthcare Power of Attorney		
Other Directives		
General Power of Attorney		
Living Trust		
Insurance Trust		
Charitable Trust		
Minor's Trust		
Custodial Account		
Organ Donation		
Prenuptial Agreement		
Post-Nuptial Agreement		
Divorce Decree		
Citizenship Papers		
Burial Agreement		
Retirement Beneficiary Designation		
Insurance Beneficiary Designation		

Power of Attorney over my assets:	
1st:	2nd:
Power of Attorney for medical: 1st:	2nd:
Decisions: 1st:	2nd:
Guardian over my property: 1st:	2nd:
Guardian over my person: 1st:	2nd:
It is my desire that those having the above guardian being appointed, unless my family	powers of attorney act on my behalf rather than a y believes guardianship is necessary.
In the event of my incapacity, I DO possible, taking into account the cost.	DO NOT want to be kept at home for as long as
I Have Do Not Have a divorce de made after I am disabled or after my death	ecree that may require that certain payments be
General Information	
I Do Do Not have a safe deposit It can be found:	box.
The key can be found:	
The following people have signature author	rity on the box:
Name:	Phone:
Name:	Phone:

		222
I Do Do Not have a personal safe.	<	000
The combination is:		00
The safe can be found:		3222
I Have Have Not attached a list of the persons I want to receive my personal property when I die.		2222
I may receive inheritance from:		999
Upon my death, my heirs 🔲 Will 🔲 Will Not receive a distribution from a trust.		666
If yes, the trust instrument was created by:		652
The trust instrument can be found:		222
I Am Am Not currently the trustee for a trust. If yes, the trust document is located at:		2222
I Am Am Not a beneficiary of a trust. If yes, the trust document is located at:		553335555555555555555555555555555555555
If you are unable to speak for yourself, your loved ones may need immediate access to important identifying information such as your Social Security number, driver's license number, passport number and passwords for important accounts such as banking, bill payment and email. To whom have you granted access to this information?		8
Has this person been told where these important numbers and passwords are stored?		222
I Am Am Not entitled to military benefits.		222222
I Am Am Not entitled to other benefits.		222222222222222222222222222222222222222
	29	722

I am a member of the following religious group(s):

I am a member of the following fraternal group(s):

I presently carry the following credit card(s):

My important records can be found:

My home filing cab	oinet
--------------------	-------

- My safe deposit box
- My home safe
- My attorney's office
- My financial planner's office

Other: _____

In the event of my death, I have the following wishes:

Funeral Home:
Cemetery:
Crematory:
Plot/Drawer #:
Minister/Rabbi:
Pallbearers:
I 🔲 Have 🔲 Have Not prepaid my burial costs for my burial plot.
I Have Have Not prepaid my burial costs for my casket.
Information can be found at:

30

		in the second se
I have a deceased Spouse Pa		Y-
who is buried at:		f ~
I 🛄 Do 🛄 Do Not wish to be buried r	next to such person:	
I 🔲 Do 🔲 Do Not have the right to be	e buried in a military cemetery.	IY
I Do Do Not want to be cremate	əd.	
Special Requests		Ŋ
Obituary Reading:		
Tempetene Frequencia		
Tombstone Engraving:		
Organs for Donation:		
In lieu of flowers, please ask for donatior	ns to:	
Other special requests		
Family History		
	State Date	
	and	
	and and	
My children are:		
Name:	Born:	
	Born:	
Name:	Born:	
Name:	Born:	
I have no children		3

C

Desires for My Family

I Have Do Not Have detailed information on my family's history.

When I am gone, I hope my family will learn from my experiences:

The most important thing I have done in my life is:

How would I like to be remembered:

When the two the two the two the two the two tests and tests a

ACT

Now What? It's time to take action!

Do not wait; the time will never be 'just right.' Start where you stand and work with whatever tools you may have at your command, and better tools will be found as you go along. - George Herbert

Without knowledge, action is useless and knowledge without action is futile.

- Abu Bakr

Action Checklist

- Begin the Conversation with key family and friends.
- Obtain and complete appropriate healthcare documents.
- Set a date to have additional conversations and share copies of your documents with:
 - Person selected as your Healthcare Power of Attorney
 - Close family
 - ____ Extended family
 - ____ Friends
 - ____ Doctor
 - ____ Attorney
 - Clergy
 - ___ Others

Continue the conversation. Set a date to review your documents every year.

Date: _____

EN?

Reflective Thoughts

- Now, it's the easy part. It's time to take action. You've educated yourself. You've thought about what matters most to you. You've communicated to important people. You've documented. Now, you just have to follow through!
- Make copies of your advance care documents. Email everyone you know and tell them
 you have begun the conversation about your end-of-life wishes. Share these documents
 with those who don't live close by. Loved ones who do not live close may be the ones to
 cause conflict when it is time to make hard decisions and implement your wishes. This may
 happen because they feel guilty. By sharing your wishes with them, you have a chance to
 save them from that guilt. Remember, these documents are a gift to those you care about.

- Speak to the doctors who oversee your healthcare. Provide them with your documents. Healthcare workers may be your biggest advocates. They need to know what you want them to advocate.
- Revisit your advance care documents each year. Life is always changing, so your thoughts and decisions may change throughout the years. That's okay!

Other Details

EMPOWER

What good is having a gift if you do not share it with others?

Now that you have begun the conversation about advance care planning, please encourage others to do the same. You know the benefits and challenges of this process, so you can be a wonderful resource for family and friends who would like to do the same.

Share your experience with others, including:

- Family and friends
- Neighbors
- Fellow church members
- Social networking contacts
- On the Begin the Conversation Facebook and Twitter pages:
 f/begintheconversation and b/begintheconvo

Seek out advance care planning programs and initiatives in your area. Volunteer to help spread the message. Encourage others to visit begintheconversation.org.

Make a list of people you would like to empower.



Reflective Thoughts

- Share your journey. You could be a huge influence on how others face death.
- It is freeing to know if something happens to you, your plan is ready to implement. Go do something on your bucket list to celebrate. Life is short. Every moment matters.
- It's time to empower others. Email your bucket list to someone and encourage that person to Begin the Conversation. Tell them to visit www.BeginTheConversation.org.

Finding your voice is hard, but you did it. Be proud!



Advance Care Planning (ACP): An ongoing process of conversations between you, your family and loved ones, and your healthcare providers that includes the communication and documentation of your values, beliefs, and wishes for future healthcare treatments. ACP includes all types of care you would or would not want to receive if you are unable to communicate your choices.

Advance Directive: A legal document that states the medical treatments and/or life-sustaining measures you would or would not want should an end-of-life situation occur and you are unable to communicate your choices. It is your written healthcare plan.

Advance Instruction for Mental Health: A legal document that tells healthcare providers what types of mental health treatments you want and don't want. Your mental health instructions can be included in this separate document or combined with a Healthcare Power of Attorney or General Power of Attorney.

Antibiotics: Medications used to fight infections.

Anatomical Study: A person may allow his/her body to be studied after death by scientists and other healthcare-related researchers to gain knowledge about certain diseases and the dying process. This may eventually lead to improved care of others living with similar conditions.

Artificial Nutrition Hydration (fluids): When you are unable to eat or drink on your own, nutrition and hydration can be administered into your stomach through a feeding tube.

Autopsy: An examination of your body after your death to determine the cause of death or the extent of changes produced by a disease

Cardio-pulmonary Resuscitation (CPR): When your heart and/or breathing stops, CPR can be used to start them again. It can be done through mouth-to-mouth resuscitation, chest compressions, or defibrillator machines.

Decision-Making Ability (Capacity): The ability to make decisions. A person has the ability and right to make his/her own healthcare decisions unless it is shown he/she cannot understand, communicate, or process information needed to make those decisions.

Disposition of Remains: A few options exist for the final placement of your body after death and include burial and cremation. Having conversations with loved ones about these options before death can help alleviate possible conflict.

Do Not Resuscitate Order (DNR): A medical order obtained through your physician, the DNR indicates you do not want to receive resuscitation attempted if your heart or breathing stops.

Electroconvulsive Treatment (ECT): A procedure in which electric currents are passed through the brain. These currents can cause changes in the brain that can reverse symptoms of certain types of mental illness when other treatments do not work.

Feeding Tube: A flexible tube that is inserted through the pharynx and into the stomach through which liquid food is passed. Feeding tubes provide nutrition for those who cannot obtain it by mouth, are unable to swallow safely, or need supplemental nutrition.

Guardian: A guardian is a person who is appointed to act on your behalf if you are unable to make your own decisions and there are no other people able or available.

Healthcare Power of Attorney (document): A legal document you prepare that names another person to be your healthcare decision-maker when you are unable to communicate your own choices.

HIPAA Release Form: A legal document that authorizes the release of your protected healthcare information to a specified person. It can include all healthcare information or can stipulate certain details be excluded.

Hospice Care: Hospice provides healthcare services and support for those living with advance illness and focuses on pain relief and symptom management, patient and family assistance, and end-of-life education and support.

Intubation: Intubation is the passage of a tube through your mouth into your lungs. Ventilation is when air is passed through that tube to allow you to breath.

IV Fluids: Liquids, such as medicine, blood, or nutrients, that are administered directly into a vein.

Life Support/Life-Sustaining Treatments: These are medical procedures that maintain your bodily functions (i.e. breathing, heart-beating) when you are incapable of doing them independently. They can include procedures such as ventilation, dialysis, surgery, transfusions, antibiotics, and artificial nutrition and hydration.

Living Will (document): A legal document that expresses your choices related to future healthcare treatments and life-sustaining measures at end of life.

Natural Death: A natural death occurs when you decide to not have treatments or measures to delay the moment of death. It applies only when death is near and will happen from natural causes.

MOST/POLST: A national movement, the POLST (Physicians Orders for Life Sustaining Measures) was started to improve quality of healthcare by translating people's choices into medical orders. It is the basis for the MOST documents (Medical Orders for Scope of Treatment) and includes communication between you, your decision-making agents, and your healthcare providers.

Organ, Eye, and Tissue Donation: To give organs, eyes, or tissue to another person in medical need, you should document your wishes and communicate them to loved ones.

Palliative Care: Medical care to relieve pain, discomfort, or distress. It does not include curative treatments or life-sustaining measures; nor does it include any measures meant to hasten or expedite death. Palliative care can be provided at any time during your illness to alleviate symptoms or pain.

Revoke/Revocation: To put an end to or discontinue an advance care planning document. Revocation processes can include destroying the forms or creating a new form. If you do revoke an ACP document, it should be communicated to your healthcare agents and providers.

Surrogate/ Proxy: A person with the ability and authority to make healthcare-related decisions on your behalf. This person could be your next of kin, an appointed representative, or your Healthcare Power of Attorney (if the form is in place).

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RESOURCES

National Resources

AARP: www.aarp.org

Aging with Dignity (Five Wishes): www.agingwithdignity.org Alzheimer's Association: www.alz.org American Bar Association: www.americanbar.org/aba.html Begin the Conversation: www.begintheconversation.org Caring Connections: www.caringinfo.org Carolinas Center for Hospice and End of Life Care: www.cchospice.org Center for Practical Bioethics: www.practicalbioethics.org Consider the Conversation: www.considertheconversation.org Donate Life America: **donatelife.net** National Cancer Institute: www.cancer.gov National Healthcare Decisions Day: www.nhdd.org National Hospice & Palliative Care Organization: www.nhpco.org National Institute on Aging: www.nia.nih.gov National POLST Paradigm: www.polst.org U.S. Department of Health & Human Services: www.ncdhhs.gov U.S. Living Will Registry: liv-will1.uslivingwillregistry.com/forms.html

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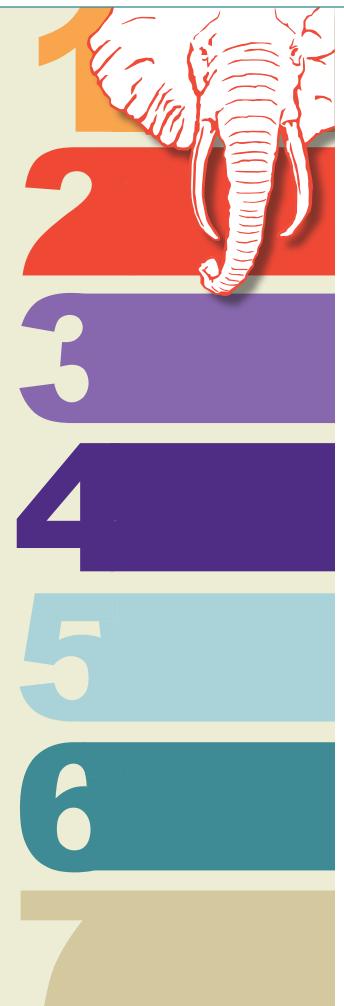
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BEGINTHE CONVERSATION • ORG

Certificate of Completion

I FACED THE ELEPHANT IN THE ROOM

Name

Date

Additional Thoughts/Notes	

More	Thoughts:
------	-----------

Add additional documents here.

- Letters to your loved ones
- Your signed, completed advance care documents
- Photos
- Other documents you may want your loved ones to have if you are unable to speak for yourself



BEGINTHE CONVERSATION • ORG

7 STEP WORKBOOK FOR ADVANCE CARE PLANNING

In life we prepare for everything College, marriage, a baby, retirement But we never BEGIN the conversation about the end

In our busy world, we rarely have quiet moments to reflect on our hearts' desires. When we do, we don't want to think about death, especially our own. We often ignore the possibility of death until a crisis occurs and we see those we love most experience pain, sickness, injury or trauma.

This workbook has been created to help you think about what you would want if you were sick or injured and could not communicate with others. Some questions will be hard to reflect upon, but avoiding these situations does not guarantee an escape from death. The only promise life provides us is that each of us will one day face death.

This workbook is an opportunity for you to discover how you want your final months, final days and final hours lived. It can become a great swan song, if you embrace it.

EDUCATE. PREPARE. COMMUNICATE. DOCUMENT. ACT. EMPOWER. Take the first step... BEGIN THE CONVERSATION It's Time!

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