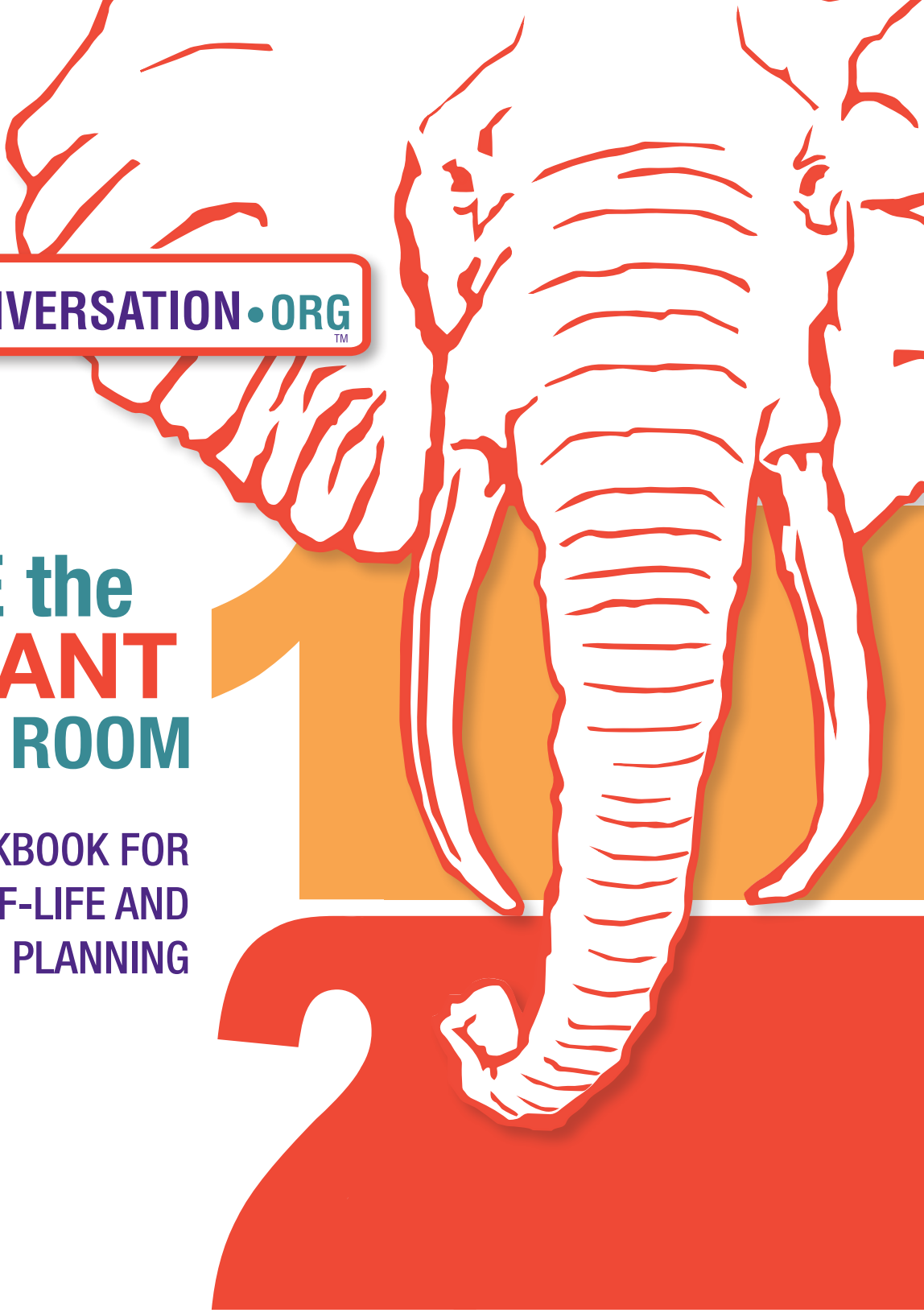
BEGIN THE CONVERSATION • ORG™

It's Time to FACE the ELEPHANT IN THE ROOM

3-STEP WORKBOOK FOR END-OF-LIFE AND HEALTHCARE PLANNING



THIRD EDITION
ACT NOW!

BEGIN THE CONVERSATION
Presented by Lower Cape Fear LifeCare

BEGIN THE CONVERSATION • ORG™

Introduction

In our busy world, we rarely have quiet moments to reflect on our own lives. 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 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 will not guarantee an escape from death. The only promise life provides us is that each of us will one day face death. This workbook creates an opportunity for you to plan how you want your final months, final days and final hours lived.

What is BeginTheConversation.org?

BeginTheConversation.org is a public education program created by a team at Lower Cape Fear LifeCare (LCFL) in Wilmington, N.C. The program was designed to empower people to complete their advance care planning documents and have hard conversations about their healthcare and end-of-life wishes, but Begin the Conversation is much more than that.

The heart of Begin the Conversation is in encouraging everyone to plan their own end-of-life journeys and to make sure they tell their friends and loved ones exactly how they want to face end of life. Paying attention to the details and planning for them matters. Details such as:

- If you could, where would you choose to die? At home? At a hospital or other facility?
- Do you want people by your bedside? Who would that include?
- If you were living out your last days, would you want your favorite flowers in your room or your favorite music playing?
- Do you want to write your loved ones a letter or record a video message to help provide closure after you are gone?

This Begin the Conversation workbook has been created to help you think about these things and so much more. We want to encourage you to think about things you may have been avoiding and will empower you to plan the end of life you want. We have included tools and resources that will help you Begin the Conversation about these decisions with those you love, and we hope once you have finished you will encourage others to Begin the Conversation, too.

A study from the Johns Hopkins Bloomberg School of Public Health found two-thirds of respondents did not have end-of life or healthcare plans 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 end-of-life planning and communicating your healthcare choices. Not only is it important for you to express your choices, it is a **GIFT** (Giving Information for Tomorrow) for your family.

Begin the Conversation can help you figure out what you want if something happens to you.
By having these conversations today – before a crisis occurs – you can decide what you would want if something happens, whether it's a tragic accident or old age or illness. These important conversations can help prepare your friends and family because they will know your wishes. It's a **GIFT.**

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

DISCLAIMER: Information in this workbook may be used as a guideline, but should not be considered as legal advice. Each situation is unique and should be discussed with your family members, healthcare providers, personal attorneys and/or certified financial planners.

Begin the Conversation is a public education program created by Lower Cape Fear LifeCare in Wilmington, N.C. to motivate people to Begin the Conversation about end-of-life and healthcare choices, as well as to complete advance care planning documents to support those choices.

phone 877.473.4103 • info@begintheconversation.org
www.BeginTheConversation.org

People are saying this about Begin the Conversation:

I was able to relate to the real stories and the information also helped me see this as a way to help others. I appreciated the different perspectives on the issues. 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 workbook has provided me with a new perspective and appreciation about advance care planning and its purpose. My family and I will definitely Begin the Conversation…

- Community Member

"Excellent program!"

I really appreciate these resources. The new information from the doctor's and patient's perspectives 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!

- Hospice Family Member

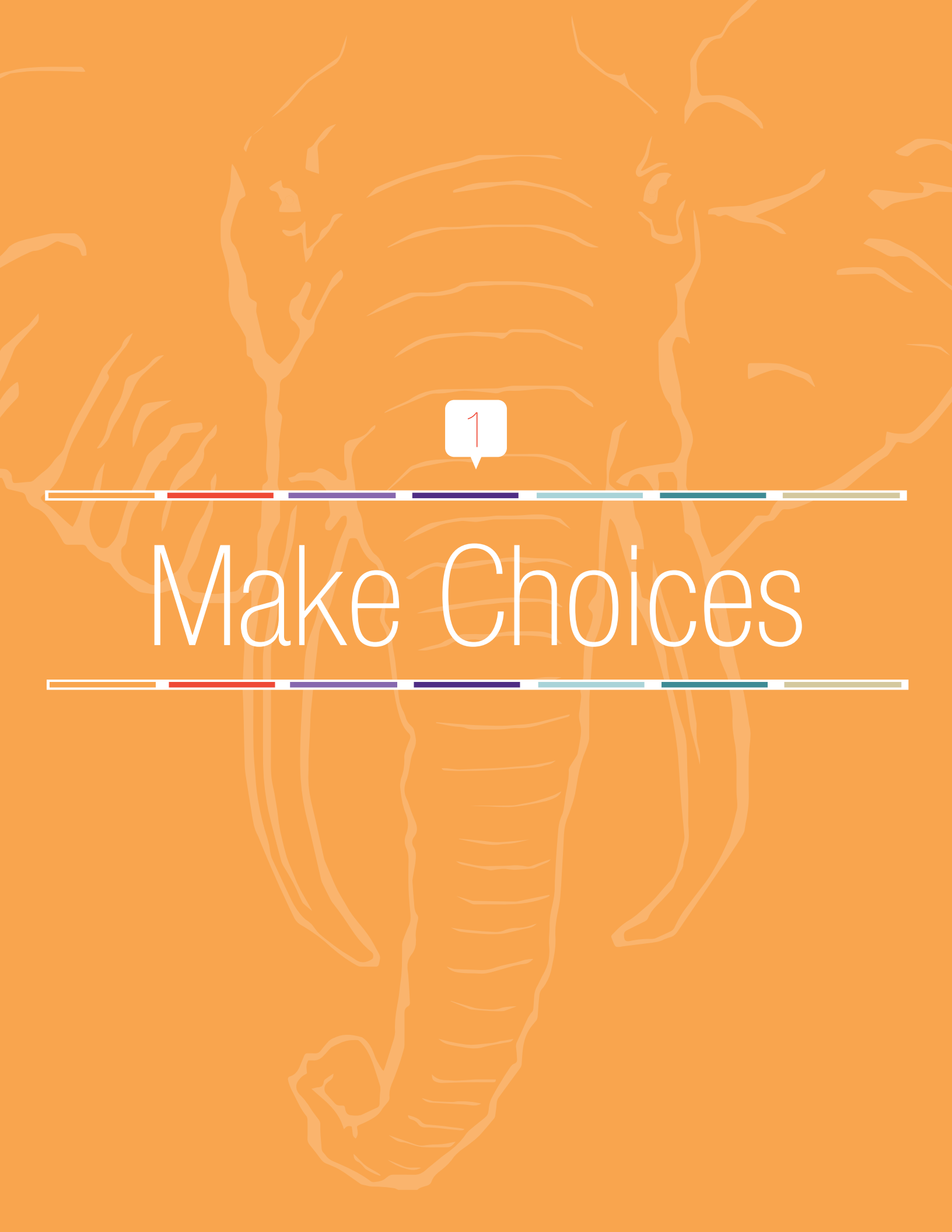
"I will be spreading the word to others."

"Thank you!"

Thank you! Your speakers were very knowledgeable and compassionate and have given me the motivation to help me through this important process, not only with my parishioners, but also with my own family.

- Community Clergy Family Member

"Very much worth my time!"



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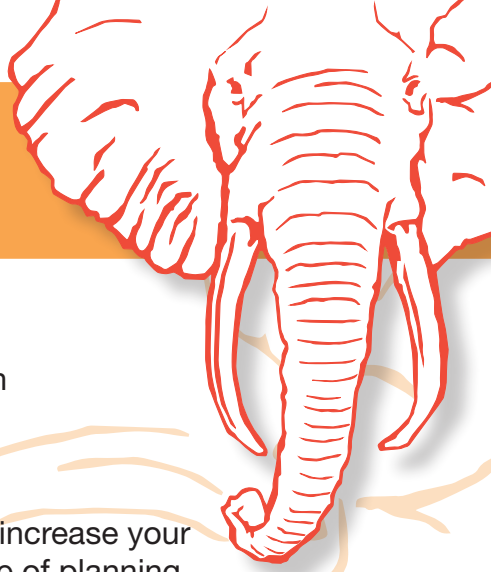
Make Choices

1 Make Choices



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 may make it easier for you, your doctor and your loved ones to ensure your wishes are honored.

It is helpful to begin by learning about advance care planning. This can increase your knowledge about healthcare and end-of-life choices and the importance of planning. It 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?

End-of-life and healthcare planning is often referred to as advance care planning (ACP). It empowers you to make decisions about the care you want if you cannot speak for yourself. It includes healthcare decisions and related healthcare documents, as well as end-of-life planning. Adults of all ages, even as young as 18, are encouraged to Begin the Conversation today, long before a healthcare crisis occurs. These conversations can help reduce your stress and anxiety while improving your care. It's also a **GIFT (Giving Information for Tomorrow)** to those you love.

Why... is advance care planning important?

It helps ensure your wishes are honored when you are unable to communicate for yourself.

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

Reality: People without advance care planning are physically moved from one setting to another an average of three times in the last few weeks of life.

Reality: Having a Living Will is associated with decreased likelihood of dying in a hospital.

Reality: Less than one third of American adults have end-of-life and healthcare documents expressing their wishes.

About 80% of people say they don't want their life extended by machines.
Reality: 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 for anyone who:

- Has specific or unique healthcare preferences
- Wants to give peace of mind to family members
- Likes to have a say in his or her healthcare decisions
- Wants to live well, even through his or her own death
- Is living with serious, advanced illness
- Is living with chronic illness, either potential or realized

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 decisions change
- When you are 18 or older

Remember, it is vitally important for you to talk about your end-of-life and healthcare wishes 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 end-of-life and healthcare 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, move on to the next step.

Reflective Thoughts

- Learn from others.
- This is a time to pause, reflect and listen to your inner 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?

Resources

The following websites provide additional information for end-of-life and healthcare planning.

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**

Center for Practical Bioethics: **www.practicalbioethics.org**

Death with Dignity: **www.deathwithdignity.org**

Donate Life America: **www.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.hhs.gov**

FACTS AND STATS
ADVANCE CARE PLANNING

- 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*

- **21%** of people say they haven't had the conversation because they don't want to upset their loved ones, while **53%** admit they'd be relieved if their loves ones actually began the conversation.
  ** The Conversation Project Naional Survey, 2018*

- Only **28%** of home healthcare patients, 65% of nursing home residents and 88% of hospice patients have advance care planning documents on record.
  ** Jones, 2011*

- **80%** of people say they would want to talk with their doctor about future treatment wishes when facing end of life. However, only about **18%** report actually having this conversation with their doctor.
  ** California HealthCare Foundation, 2012; Kaiser Family Foundation, 2017*

- A study with a nationally representative sample reported that only **18%** of ethnic minority participants completed advance directives compared to **34%** of white respondents.
  ** Hong/Eun-Hye/Johnson/Adamek, 2018*

- **82%** of estate-planning attorneys surveyed recommended having discussions 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*

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. Consider the future. Write those decisions down and add to them.
- Begin by including loved ones in the planning and 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 talk about your end-of-life wishes.
- Begin by thinking about things you do and you don't want at end-of-life.

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 choose where I die (at home, in a hospital, at a hospice care center, etc.).

LET'S GET STARTED

What would you change about how you live if time were limited? What things are on your bucket list?

What makes life worth living for you?

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

Pain Management Choices

If you were faced with end-of-life do you:

- ☐ Want pain management to include all drugs to keep you from being in pain?
- ☐ Want pain management as long as you can remain aware of your surroundings and communicate with your loved ones?
- ☐ Want pain management, but want 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 requests for your caregivers are:

Bathing: _____

Grooming: _____

Other personal care options: _____

_____

Matters of the Heart

When you are in the last few days of your life:

I want these people at my bedside:

_____

I ☐ DO ☐ DO NOT want someone praying at my bedside. If yes, who?

_____

I ☐ DO ☐ DO NOT want my favorite TV show on. It is _____

I ☐ DO ☐ DO NOT want fresh flowers 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 to ask forgiveness from or provide forgiveness to? If yes, who is it and how do you plan to address this?

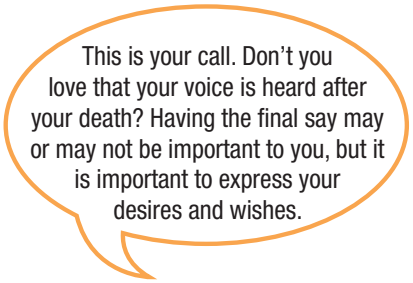
Recommendation:
Don't wait to forgive someone or ask forgiveness. Have courage to move forward before you face end of life. You might heal a wound that does not need to wait until you are dying.

_____

Funeral/Burial

Some people may like to have a funeral or end-of-life celebration before they die. They like the idea of having a celebration 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 want to be cremated? Do you have a funeral plan?



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

Funeral Home: _____

Cemetery: _____

Crematory: _____

Plot/Drawer #: _____

Minister/Rabbi/Officiant: _____

Pallbearers: _____

I ☐ Have ☐ Have Not prepaid for my burial plot.

I ☐ Have ☐ Have Not prepaid for my casket.

I ☐ Have ☐ Have Not prepaid for my cremation.

Information can be found at: _____

I have a deceased ☐ Spouse ☐ Parent ☐ Child

who is buried at: _____

I ☐ Do ☐ Do Not wish to be buried next to such person: _____

I ☐ Do ☐ Do Not have the right to be buried in a military cemetery.

I ☐ Do ☐ Do Not want to be cremated.

If you would like to be cremated, do you want someone to keep your ashes or have them buried/spread in a specific location?

_____

Tombstone Engraving:

_____

Do you wish to donate your organs?

☐ I wish to donate any organs/eyes/tissue that would be appropriate/helpful to someone in need

☐ I wish to donate only certain organs/eyes/tissue
(please list): _____

☐ I do not wish to donate my organs/eyes/tissue

Do you have a plan to donate your body for education/research?

☐ Yes ☐ No
If yes, the institution is: _____

In lieu of flowers, please ask for donations to: _____

Other special requests

_____

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.

Additional thoughts for your memorial service/celebration of life.

Obituary

☐ I want a published obituary.

Consider writing your own obituary with the information you want it to contain. Possibilities can include the date and place of your birth, immediate family members (living and deceased), professional and personal accomplishments, civic or religious affiliations, or any advice and words of wisdom you'd like to share. Feel free to use additional pages if needed.

Pet Care

In the event of my death, please ensure the care of my pets:

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.

Number of pets _____.

Names and type of pets:

If I am unable to care for my pet, my 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*

My pet has special needs (allergies, health conditions, preferred food etc.):

_____

Questions for Reflection

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

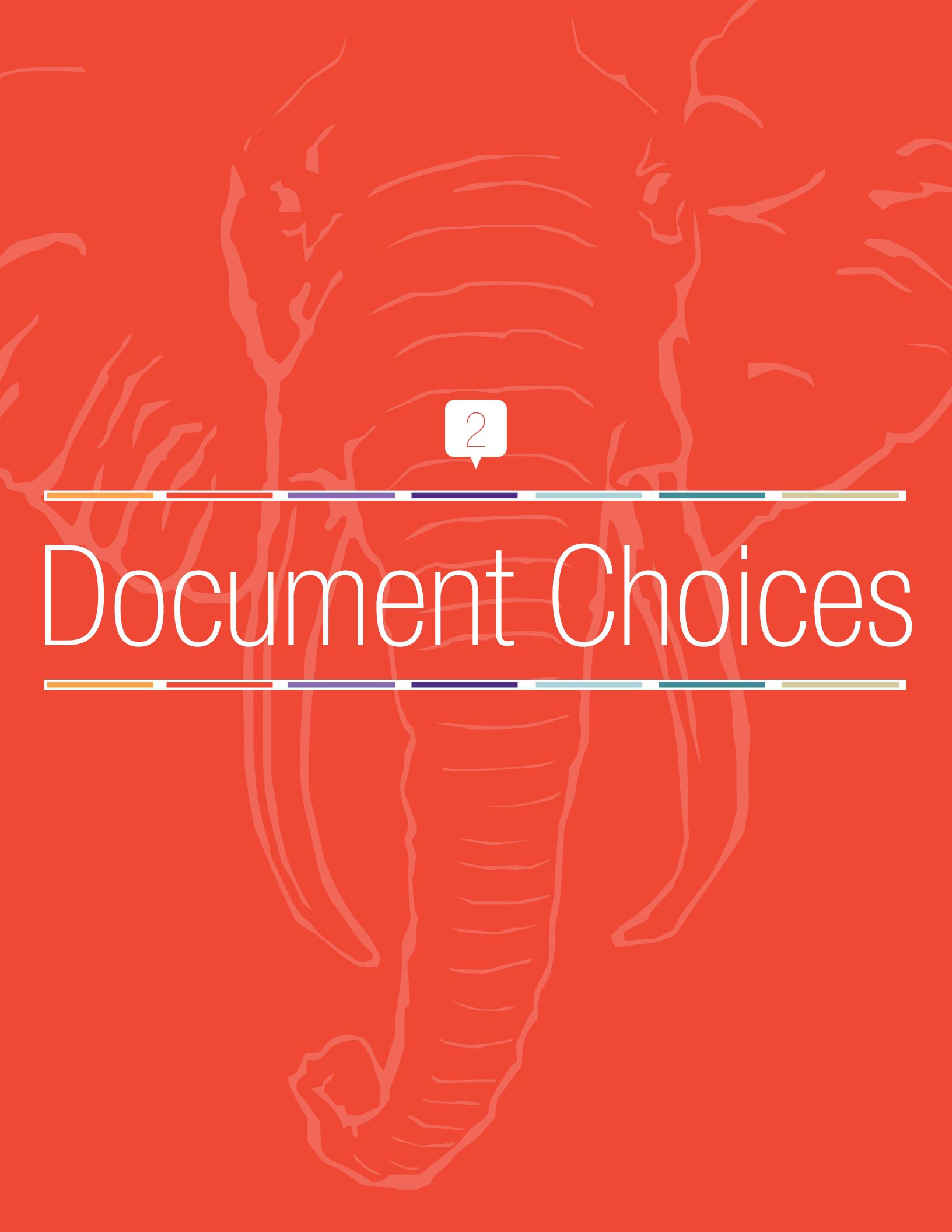
_____

This is how would I like to be remembered:

_____

Words of advice or wisdom for my family and loved ones:

_____



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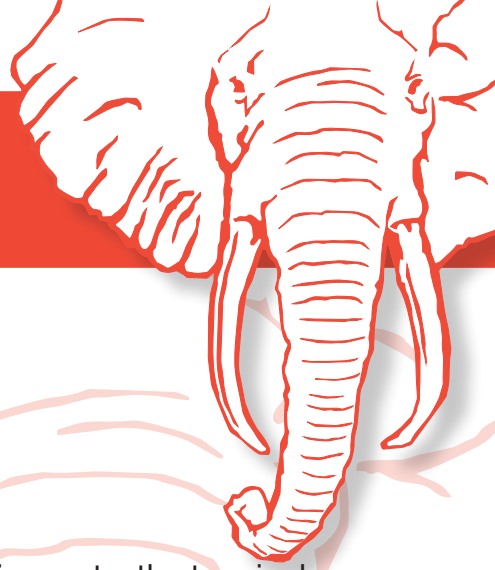
Document Choices

2 Document Choices



Two key healthcare documents can assist in your healthcare planning – a Living Will and a Healthcare Power of Attorney form.

Though the names of healthcare planning forms, their execution requirements, the terminology used, and related laws often vary from state to state, there are a few basic documents that can assist you in communicating medical preferences and decisions in the event that you cannot. This section will walk you through the Healthcare Power of Attorney form and the Living Will, two legal documents with no cost to create (unless attorney or notary services are needed), that only go into effect once the ability to communicate is lost, and do not expire. We will also examine portable medical orders, such a the Do Not Resuscitate order, as other options to express healthcare choices.

Let's do this!

This section and all other parts of this workbook are meant to help you make decisions and complete healthcare forms, but do not constitute legal documentation.

Healthcare Power of Attorney

A **Durable Power of Attorney for Healthcare** (or Healthcare Power of Attorney/HCPOA) form is a document where you appoint a healthcare advocate to make future medical decisions if you are incapacitated due to illness or injury. This advocate/agent/proxy will speak on your behalf based on your communicated wishes as well as their assessment of your best interests.

When choosing the appropriate person to serve as a HCPOA, it is important to consider a few things:

- Are they willing to accept this responsibility? This is not something to take lightly; these might be difficult and stressful times. He/she could interpret an appointment as the HCPOA as a loving responsibility... or as an unwanted burden.
- Are they able to make these decisions? Do you feel your advocate can make sound decisions when faced with varying information and opinions, both from the medical community and your family? Can he/she remain objective even during emotional situations?
- Are they available? With technology, your HCPOA doesn't have to live next door; decisions can often be made from anywhere. However, having a HCPOA with the time and capacity/presence to commit to your care can be an advantage.

Though you are only required to appoint one person as your HCPOA, many states allow for a second and third choice. However, if you choose to do that, you must list your healthcare advocates in order of preference. The HCPOA responsibilities only pass to your second choice if/when your first choice is unable or unwilling to accept them.

Let's pick your chosen few.

The person I choose as my healthcare agent is:

Name: _____ Relationship: _____

Reasons for choosing this person: _____

_____

☐ I have had a conversation with this person to discuss my healthcare wishes and his/her willingness to serve as my healthcare power of attorney.

☐ I have not had a conversation with this person, but plan on doing it on _____ .

If this person is unable or unwilling to serve as my healthcare agent, my next choises are:

Name (#2): _____ Relationship: _____

Reasons for choosing this person: _____

_____

☐ I have had a conversation with this person to discuss my healthcare wishes and his/her willingness to serve as my healthcare power of attorney.

☐ I have not had a conversation with this person, but plan on doing it on _____ .

Name (#3): _____ Relationship: _____

Reasons for choosing this person: _____

_____

☐ I have had a conversation with this person to discuss my healthcare wishes and his/her willingness to serve as my healthcare power of attorney.

☐ I have not had a conversation with this person, but plan on doing it on _____ .

Now that you have made your selections, it is time to make it official. To obtain a legal HCPOA form, visit the Resource tab at BegintheConversation.org or contact your local hospice agency.

☐ I have completed my HCPOA on _____ .

It is located here: _____ .

Reflective Thoughts

- Some HCPOA forms allow you to express special intructions or limitations for your advocate. Be sure to thoroughly discuss these items, and your reasons for them, ahead of time.
- It is important that your HCPOA is aware of other healthcare-related plans, such as your preferences for organ/eye/tissue donation, privacy matters (i.e. HIPPA release documentation), and long-term care options.
- Unfortunately, it is rare to have multiple people agree on healthcare decisions, which is why it is critical to have conversations with all your loved ones, whether they are your official HCPOA or not. Your completed documents are only as effective as the conversations you have about them.

Living Will

A **Living Will** is a document where you specify future medical treatment preferences, typically at end-of-life, if you become permanently unconscious, in a vegetative state, or beyond hope of recovery.

Before jumping into the completion of a living will, though, it might be helpful to look at the following hypothetical scenarios and jot down your thoughts and feelings.

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, doctors deliver the bad news.

What do you want them to do?

Though some years have gone by, you wouldn't consider yourself "old" by any means. However, your health has been declining for some time with several trips to the emergency room and admissions to the hospital. This most recent episode has put you on a ventilator. Doctors explain to your loved ones that it is highly unlikely (less than 10% chance) that you will experience any kind of meaningful recovery or quality of life, but that it is not entirely impossible. What would you want them to do?

What do you want them to do?

You have lived a full life and successfully made it to the twilight years. 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?

_____

Now that you have considered potential scenarios and your preferred responses, it is time to make it official. To obtain a legal Living Will form, visit the Resources tab at BegintheConversation.org or contact your local hospice agency.

☐ I have completed my Living Will on _____ .

☐ It is located here: _____ .

Generally, the purpose of a Living Will is to communicate preferences for *limitations* on life-sustaining treatments. However, if faced with injury or serious illness, your personal choice might be to *maintain* these measures. If so, you may choose not to execute a Living Will document.

☐ I have decided to **not** complete a Living Will for the following reasons:

_____

Reflective Thoughts

- Healthcare is not a perfect science. Sometimes things happen that cannot be explained medically. What is your perspective on the role of hope, faith, and miracles as it pertains to end-of-life decision-making?
- It is important to make sure your advocates and loved ones are aware of your Living Will decisions. What if they do not agree or refuse to support those decisions? Could it be a source of conflict within your family?
- This is a perfect time to define your personal feelings regarding the trade off between quantity and quality of life. What is more important to you right now?

Medical Orders

Medical Orders are documents that can help make and express decisions about end-of-life treatments, but unlike advance directives, they are not for everyone. Medical Orders are generally for those already living with advanced illness, and consequently must be completed by a medical provider. They help guide emergency and medical professionals in providing appropriate treatments, but are not meant to replace Living Wills and Healthcare Power of Attorney forms.

Medical Orders can take on a variety of forms. However, the most common documents used for healthcare planning purposes are:

- **Do Not Resuscitate (DNR)** order: A medical order obtained through your doctor, stating that you do not want to receive resuscitation (CPR) in the event that your heart or breathing stops.
- **Physician Order for Life-Sustaining Treatment (POLST)**: Depending on where you live, these portable medical orders may be referred to as MOST, COLST, MOLST, POST, etc. These forms usually include the DNR order, but also include directions for other treatment decisions, including the use of antibiotics and artifical nutrition/hydration.

Let's see if Medical Orders are right for you.

1. If you had no pulse or were not breathing, what would you recommend?

   ☐ **Attempt resuscitation (CPR)**
   Why? _____

   ☐ **DO NOT attempt resuscitation (DNR/no CPR)**
   Why? _____

   ☐ **Depends**
   On what?: _____

   ☐ **I am not able to answer**
   Why? _____

2. If you were faced with a medical emergency and unable to communicate, what would you want?

   ☐ **Full scope of treatment, including**
   - Use of intubation and other airway interventions
   - Mechanical ventilation
   - Cardioversions
   - Medical treatments; IV fluids
   - Transfer to hospital if needed

   ☐ **Limited additional interventions, including**
   - Medical treatments; IV fluids
   - Transfer to hospital if needed, but avoid intensive care
   - Do not use intubation or mechanical ventilation

   ☐ **Comfort measures only, including**
   - Medication to relieve pain and suffering
   - Appropriate positioning and wound care
   - Oxygen, suction, and manual treatment for airway obstruction for comfort
   - Keep clean, warm, and dry
   - DO NOT transfer to hospital unless comfort needs cannot be met in current location

3. If you were in a healthcare crisis, would you want antibiotics?

- ☐ Yes, if life can be prolonged
- ☐ Maybe; it will need to be determined at the time
- ☐ No, use other measures to relieve symptoms

4. If you were facing the end-of-life, would you want articial nutrition and hydration?

IV Fluids

- ☐ Use IV fluids long-term
- ☐ Use IV fluids for a defined trial period
- ☐ Do not use IV fluids; provide other comfort measures

Feeding Tubes

- ☐ Use feeding tubes long-term
- ☐ Use feeding tubes for a defined trial period
- ☐ Do not use feeding tubes; provide other comfort measures

If you feel that your answers above may warrant the completion of a medical order, please consult your personal physician or healthcare provider.

☐ I have completed a Do Not Resuscitate (DNR) order.

Date created: _____

Physician Name: _____

☐ I have completed a Physician Order for Life-Sustaining Treatment (POLST) order.

Document Name (i.e. MOST): _____

Date Created: _____

Physician Name: _____

Reflective Thoughts

- Medical orders are typically produced on brightly-colored paper and should not be individually printed/copied. Though they are meant to be kept with you, it is important that they are also documented in your medical record.
- Be sure to check your state's particular documents to see if they have expiration dates so that you can evaluate and renew if/when needed.
- Like other advance directives, be sure that your advocates and family are aware that these documents are in place.

In the KNOW

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, 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 loved ones.

Contacts

Financial Advisor/Accountant

Name: _____

Address: _____

Telephone: _____

Attorney

Name: _____

Address: _____

Telephone: _____

Insurance Agent

Name: _____

Address: _____

Telephone: _____

Employer

Name: _____

Address: _____

Telephone: _____

Accounts

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

Investments/Stocks: _____
Contact: _____
Phone: _____
Location of documents: _____

Savings: _____
Contact: _____
Phone: _____
Location of documents: _____

Liabilities: _____
Contact: _____
Phone: _____
Location of documents: _____

Pension: _____
Contact: _____
Phone: _____
Location of documents: _____

Trust: _____
Contact: _____
Phone: _____
Location of documents: _____

Social Media Accounts

Platform: _____
Username: _____
Password: _____

☐ Please shut down this account ☐ Please keep this account live/as a memorial

Platform: _____
Username: _____
Password: _____

☐ Please shut down this account ☐ Please keep this account live/as a memorial

Platform: _____

Username: _____

Password: _____

☐ Please shut down this account ☐ Please keep this account live/as a memorial

Platform: _____

Username: _____

Password: _____

☐ Please shut down this account ☐ Please keep this account live/as a memorial

Platform: _____

Username: _____

Password: _____

☐ Please shut down this account ☐ Please keep this account live/as a memorial

Policies

I have the following life insurance policies (including company-owned):

Type	Owner	Beneficiary	Face Amount	Existing Loans	Cash Value
			$	$	$
			$	$	$
			$	$	$
			$	$	$
			$	$	$
			$	$	$

Policies can be found at: _____

I have the following disability insurance policies:

Company/Agent	Where can this policy be found?

I have the following long-term care insurance policies:	
Company/Agent	Where can this policy be found?

I have the following health insurance policies:	
Company/Agent	Where can this policy be found?

I have the following other policies:		
Type	Company/Agent	Where can this policy be found?
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 premium payments to be stopped.

If I am disabled, my disability insurance policy:

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

Forms

I have executed each of the following documents and you can find them where noted:		
Document	Date Signed	Location Stored
Will		
Living Will		
Durable Power of Attorney for Healthcare		
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		

I have appointed (in the above documents) the following people to act on my behalf if I become disabled:

Power of Attorney over my assets:

1st: _____ 2nd: _____

Healthcare advocate:

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 powers of attorney act on my behalf rather than a guardian being appointed, unless my family believes guardianship is necessary.

In the event of my incapacity, I ☐ DO ☐ DO NOT want to be kept at home for as long as possible, taking into account expenses.

Other

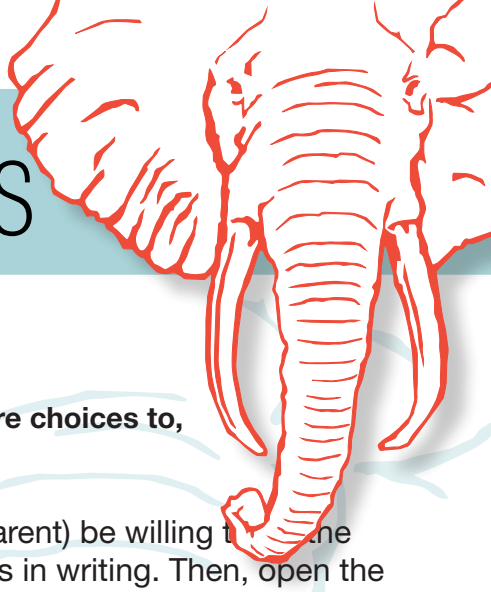
Other Special Instructions/Documentation:

_____

3

Communicate Choices

3 Communicate Choices



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 t[illegible]he 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 helpful 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 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 of 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: End-of-life and healthcare 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?"

Share Your Experience with Family and Friends

Prepare a list of people with whom you want to communicate your end-of-life choices. This is not about 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.

- ☐ 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:
  - ☐ Close family
  - ☐ Extended family
  - ☐ Friends
  - ☐ Doctor
  - ☐ Person selected as your healthcare advocate
  - ☐ Attorney
  - ☐ Clergy
  - ☐ Others

☐ Continue the conversation. Set a date to review your documents every year. National Healthcare Decisions Day is April 16 each year. We suggest reviewing your document on this day each year. **I will review my documents again on:** _____

Conversation Tools: Discuss tools from the earlier sections of this workbook with your loved ones

- What's Important to You - Page 8
- What Would You Do?- Pages 18-19
- In the Know Worksheet - Pages 21-28

Reflective Thoughts

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

- 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.
- Without communication, end-of-life and healthcare planning documents may be confusing and could leave your advocates confused and in shock.
- This does not have to be a serious conversation. It can be light-hearted and fun. Don't make a simple process complicated.
- When you communicate your wishes, you may realize you need to rethink who you originally chose to be your healthcare advocate. Your healthcare advocate needs to be able to honor your wishes. Some friends and family just can't do that.
- Speak to doctors who oversee your healthcare. Provide them with your documents. Healthcare workers may be your biggest advocates. They need to know the choices you want them to advocate for.
- Revisit your end-of-life and healthcare planning documents each year. Life is always changing, so your thoughts and decisions may change throughout the years. That's okay!

Action Checklist

- ☐ I have had the conversation with my agents and told him/her/them about my wishes.
- ☐ I have provided copies of my documents to my agents, loved ones, healthcare providers, and all relevant people.
- ☐ I will revisit my end-of-life and healthcare planning documents each year on the following dates, and if any changes are made, I will share the updated information and documents with my agents:

☐ _____ *date*

☐ _____ *date*

☐ _____ *date*

☐ _____ *date*

☐ _____ *date*

☐ _____ *date*

What good is having a gift if you don't share it with others?

Now that you have begun the conversation about your end-of-life and healthcare choices, 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, friends, and neighbors
- Fellow church members
- Social networking contacts
- On the Begin the Conversation Facebook page: /BeginTheConversation

Seek out end-of-life and healthcare 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 end of life.
- 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 everyone to visit **BeginTheConversation.org.**

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

Glossary

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 and end-of-life plans. 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 a defibrillator.

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 final placement of your body after death including burial and cremation. It's a gift to make sure your loved ones know what you want.

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

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

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 Advocate/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 advocate.

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 with advance illness and focuses on pain relief and symptom management, patient and family assistance, and end-of-life education.

Intubation: 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 to maintain 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.

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.

Physicians Orders/Portable Medical Order: Across the United States, there are varying names for portable medical orders/physician orders for the documents that direct decisions about life-sustaining treatments. A national movement, Physicians Orders for Life-Sustaining Treatment Paradigm (POLST), has been created to facilitate honoring patient wishes by using portable medical orders and encouraging conversations about these choices. These forms do not negate the need for a healthcare advocate, proxy or Durable Power of Attorney for Healthcare. Portable medical orders are not for everyone. They are for the seriously ill. Depending on where you live, they may be referred to as COLST, MOLST, MOST, POLST or POST.

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 advocates and providers.

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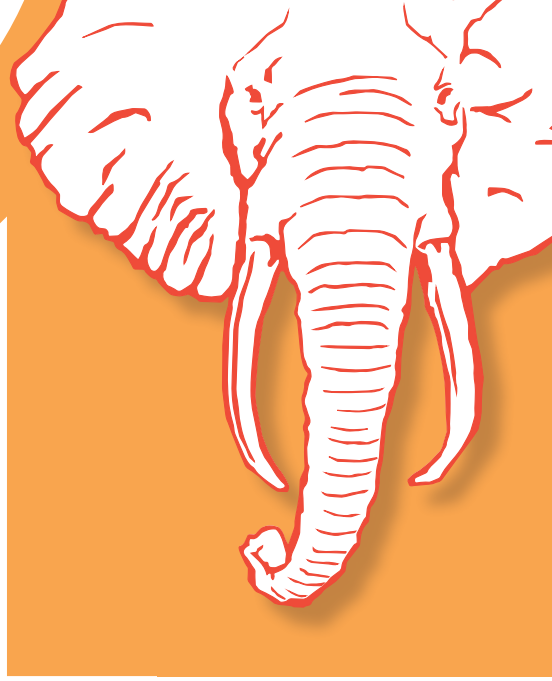
3-STEP WORKBOOK FOR END-OF-LIFE AND HEALTHCARE PLANNING



In life we prepare for everything

College, marriage, a baby, retirement

But we rarely BEGIN the conversation about the end

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.

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.

MAKE. DOCUMENT. COMMUNICATE.

Take the first step… BEGIN THE CONVERSATION

It's Time!

THIRD EDITION ACT NOW!

LOWER CAPE FEAR LifeCare