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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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:**

- **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.

- **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?
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:

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________

____________________________________________________________________
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. If you were in the last six months of your life, still had a pulse and were breathing but 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. Do not use intubation or mechanical ventilation; 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. Do not transfer to hospital unless comfort needs cannot be met in current location.

3. If you 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.
   Why? ___________________________________________________________
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 **artificial nutrition and hydration** if physically feasible
- **IV fluids** long-term if indicated
- **IV fluids for a defined trial period**
- No **IV fluids. Provide other measures to ensure comfort**
- **Feeding tube**, long-term if indicated
- 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 Orders for Scope of Treatment)

**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

__________________________________________________________ will be cared for by __________________________________________

Pet Name

__________________________________________________________ will be cared for by __________________________________________

Pet Name

__________________________________________________________ will be cared for by __________________________________________

Pet Name

__________________________________________________________ will be cared for by __________________________________________

Pet Name

Does your pet have special needs (allergies, health conditions, preferred food etc.)? ______________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

__________________________________________________________

Matters of the Heart

When your are in the last few days of your life, your desires are:

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. __________________________________________
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.

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

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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.)

Name: ______________________________________________________

Contact 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 ____________

Name: ______________________________________________________

Contact 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 ____________

Name: ______________________________________________________

Contact 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 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
  - Colorado
  - Georgia
  - Hawaii
  - Idaho
  - Louisiana
  - Montana
  - New York
  - 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.
- Attorneys are not required to execute these documents, but you are encouraged to seek legal counsel if you have any questions.
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: ______________________

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

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________

___________________________________________
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 breathe.

**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).