

Preparing & Planning

For Life's Final Chapter



AgeWell
MIDDLE TENNESSEE



PREPARING AND PLANNING FOR LIFE'S FINAL CHAPTER

Just as you have planned and prepared for other chapters in your life, it is important to consider your wishes for end of life care and discuss your choices with your doctor and loved ones. Planning ahead and sharing those plans can ensure that one's wishes are followed. This can be a true gift to family members, sparing them from making complex decisions in a time of crisis.

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AgeWell Middle Tennessee addresses the unmet needs of older adults and caregivers through information, advocacy and education and by being a catalyst for comprehensive solutions.

This booklet is designed to help you and your loved ones understand some of the common questions regarding end of life care and decision-making. After all, planning ahead helps ensure your wishes are honored and can help you make informed and thoughtful decisions before a crisis may occur.

Through a generous donation from **The West End Home Foundation**, an End of Life Committee was formed to create this booklet. Several leaders from the community contributed to the discussion leading up to the creation of this publication.

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INTRODUCTION

END OF LIFE CARE is the term used to describe the support and medical care given near death, whether from a sudden illness, a life-ending disease or old age.

ADVANCE DIRECTIVES refers to the legal documents that allow you to convey your decisions around end of life care. These documents provide a way for you to communicate your wishes to friends, family, and health care professionals. Advance Directives should include both a document that allows you to (1) make your own end of life wishes known if you are unable to speak for yourself and (2) allows you to appoint someone to make medical decisions on your behalf in the event that you are unable or too sick to speak for yourself. Advance Directives include Advance Care Plan/Living Will, DNR/POST Order, Appointment of Health Care Agent/Durable Power of Attorney for Health Care or any other legal document outlining your end of life wishes (Learn more in the Financial & Legal Issues Chapter).

The journey of life is filled with many chapters and paths. Just as birth is a natural part of the life cycle, so is death. It is hard to face the idea of your own death or that of loved ones. However, it is important to educate yourself and make the necessary decisions regarding end of life issues and END OF LIFE CARE.

End of life considerations are multifaceted and vary depending on the individual and what is important to him or her. These considerations range from basic care needs to the use of complex medical interventions, from staying at home or in a medical facility to how to cover the cost of care, and the legacy you want to leave. End of life considerations are also impacted by one's cultural norms, religious beliefs, support systems and concern for loved ones that will be left behind.

This planning starts with asking yourself some crucial questions to determine what is most important to you. The second step is to educate yourself and family members on the options and implications of end of life care. Lastly, you will need to document your decisions, such as with written Advance Directives.

“THE FIVE C’S”

Below are the five concepts that are likely to inform decision making around end of life wishes:

COMFORT

Relief and control of distressing symptoms remain a top priority. PALLIATIVE CARE can provide invaluable help in achieving this goal throughout an advanced illness.

COMPANIONSHIP

Fear of isolation and abandonment is a major concern for individuals with a LIFE-LIMITING ILLNESS. Loved ones, friends, and medical providers should be encouraged to maintain contact and communicate caring. This can help lessen feelings of despair and assist the individual in finding meaning in their lives.

CLOSURE

This involves practical issues, such as making wills, recording burial wishes, and designating an executor, as well as emotional issues, such as reconciliation, saying “good-bye” to loved ones and identifying meaningful events in one’s life. Fulfilling these goals help make a peaceful passing.

CONTROL

Whether it is perceived or real, the loss of control is one of the most emotionally devastating consequences of a life-limiting illness. Friends, family and health care providers should do whatever they can to allow the person with the illness to participate in his or her care and decision making.

COST

Often a disproportionately high percentage of medical expenses occur during the last few weeks of life. Intensive care units and sophisticated life support measures account for a large part of these expenses.

No one wants to be denied appropriate lifesaving medical care because of increased cost; however, many people fear they will deplete their financial resources on health related needs at end of life. The key may be to discuss the benefit versus the burden of the medical interventions. Asking your medical provider a few simple questions may help, such as:

- Are the treatments going to make it possible for you to live independently or restore an ability that you have lost?
- Will this medical intervention improve your quality of life or reduce your pain and discomfort?

PALLIATIVE CARE is a treatment approach that aims to improve the quality of life of people facing serious or chronic illness. It concentrates on pain and symptom management, communication, and coordination of the patient’s care. It is NOT hospice care and is appropriate during any stage of an illness.

LIFE-LIMITING ILLNESS is a chronic disease or condition that doesn’t respond to curative treatments, leading to a terminal diagnosis.

SO...WHERE DO I START?

At this point, you may be asking yourself that question! As with many other important issues, the first step is to educate oneself. This booklet will start you on your journey, encouraging you to consider tough questions, document your wishes, and share them with those around you. Let's start by considering the types of decisions you will need to make. Common terms are defined throughout the booklet in the gray sidebar, as well as in the glossary on page 30.

END OF LIFE CONSIDERATIONS:

DESIGNATED DECISION MAKER

- If you are unable to communicate your wishes, who should make decisions for you regarding medical interventions, including, but not limited to the use of a ventilator (also called a breathing machine or life support), feeding tubes, I.V. fluids, antibiotics, and pain medication?
- Does that person know that you want them to act on your behalf and have you completed the proper paperwork to give them that authority?

MEDICAL INTERVENTIONS

- Would you want medical treatments provided to sustain life at all costs if those treatments will not be beneficial and may cause discomfort?
- What are your thoughts and values around sustaining life artificially?
- If you have a terminal illness, do you wish to be resuscitated if you stop breathing or your heart stops?
- If you have no appetite or can no longer take food by mouth, would you want to have a feeding tube or other form of artificial nutrition?

ADVANCE DIRECTIVES

- Have you written down your wishes regarding end of life care?
- Have you gotten the document notarized or witnessed?

- Have you discussed those wishes and provided a copy of that document to the person you are appointing to make decisions on your behalf?
- If you do not want emergency personnel to attempt to restart your heart and breathing, have you filled out the proper forms?

A PLANNED HOME-GOING

- Where would you want to be at the end of life? A medical facility, home, or other environment?
- Do you know what choices are likely to lead to each place?
- Who would you want with you if you are dying? Family, friends, clergy, pets, or others?

SPIRITUALITY & CULTURE

- How do your beliefs impact your end of life wishes?
- What fears do you have around death and dying and who can you talk to about those fears?
- What traditions or customs do you want incorporated into your funeral or memorial services? Have you informed your loved ones of these wishes?

HOSPICE

- What is hospice?
- Does hospice put any limits on the medical treatment you will receive?
- Does accepting hospice create conflict with your values or religious beliefs?
- Where can hospice care be provided if you need 24/7 care? Will your family be able to care for you?

LEAVING A LEGACY

- What are your priorities for your legacy?
- Do you need a will?
- If you have completed a will, how long has it been since you reviewed it and have your circumstances changed since the will was executed?

- Have you made plans for who will handle your estate?
- Also important to review beneficiary designations for accounts/policies like life insurance. These trump whatever is in a will.

Hopefully, these questions will help you begin to think about this often avoided, but very important subject. The time to think about and plan for end of life care is before the crisis or illness. Most of all, planning helps you stay in control and continue to make your own decisions.

Now is the time to learn about your options and know how to document your wishes. The next part of this booklet will help guide you through this process.

PRACTICAL & ETHICAL CONCERNS AROUND END OF LIFE CARE

ARTIFICIALLY PROVIDED FLUIDS AND NUTRITION

is a method of providing food and water to seriously ill patients who are unable or unwilling to eat. Fluids and nutrition can be given through an IV, or a Nasogastric (NG) tube, which goes through the nose, down the throat and into the stomach. Sometimes the NG tube is called a Dobhoff tube. Unfortunately, both of these methods can only be used temporarily because of the complications that develop if they are used too long. The only permanent feeding tube is a PEG (permanent endoscopic gastrostomy), which goes straight through the abdomen and into the stomach. A PEG tube involves minor surgery. All these methods typically involve continuous supervision by medical staff and present the risk of injury or infection and other adverse effects.

When we think about end of life care or certain medical treatments and interventions, it is first important to examine our own personal thoughts, feelings, and values regarding our care and medical decisions. This is why it is important to ask your doctor questions. It also gives you and your doctor the chance to give or clarify important personal or medical information. You should also discuss these issues with your family, friends, or religious mentors.

People often have serious concerns about ethical or moral issues involved with providing care at the end of life. You may also have general questions about the terms and types of care described within Advance Directive forms.

This section will define common medical terms and help address some of the common questions people may have.

CONSIDERING THE USE OF ARTIFICIAL NUTRITION AND HYDRATION WHEN FACING ADVANCED, LIFE-LIMITING ILLNESS

As a life-limiting illness progresses, people often lose the ability or desire to swallow food or fluids. Many times the processes needed to digest and absorb the necessary nutrients from food have slowed down significantly or may not be

working effectively depending on the illness. Since food and water are basic staples of life when we are in good health, it is only natural for one to have concerns over the pros and cons of placing feeding tubes and IV measures for fluid and nutritional support.

People may be concerned that stopping fluids and nutritional support will result in discomfort, leading to “starvation” and dehydration. However, medical studies suggest that physical changes in the body act as natural sedatives that provide comfort. It is also important to know that agitation or discomfort can occur when nutrition and fluids are forced.

People may also be concerned that death or related secondary medical complications will result if nutrition or fluids are withheld. Artificial nutrition through tube feeding has not been shown to prevent infection or prolong survival when someone is terminally ill. Rather, tube feedings can pose significant complications such as increased risk of aspiration, often resulting in pneumonia, so the risks of such treatments must be considered. Also, feeding tubes may be uncomfortable. People who are semi-conscious or delirious often attempt to remove the feeding tubes. To prevent injury, such as

aspiration or damage to tissue, they are often restrained. It is distressing for many people to see their loved one restrained, since being tied down may decrease a person's dignity.

For these reasons, it may be more humane to avoid NG, PEG or IV feedings when an individual no longer desires or is unable to eat. However, it is also appropriate to keep food and liquids available if the person wishes to eat or drink. This allows the person to remain in control.

WHETHER OR NOT TO PERFORM CPR WHEN FACING ADVANCED, LIFE-LIMITING ILLNESS

CPR is often misrepresented in movies and television as regularly resuscitating a person who is not breathing. This gives the unrealistic expectation that CPR is always successful. In healthy individuals, CPR has a success rate of up to 70%. In patients over 60 years of age the actual survival rates are approximately 22% and 10% for patients with a late stage illness. Even when applied appropriately, CPR can result in multiple rib fractures in older adults. When cardiac activity is restored, it is rare that the patient will be able to function like he did before.

In the State of Tennessee, a healthcare professional can communicate your wishes not to be

resuscitated by completing a “Do Not Resuscitate Order (DNR)” or “Physician’s Orders for Scope of Treatment (POST)” form. In the case of an emergency, some Advance Directive forms (such as an Advance Care Plan) will not keep emergency personnel from attempting resuscitation. They are required by law to attempt resuscitation unless provided a separate directive that states otherwise, such as a DNR or POST form.

WHETHER OR NOT TO USE A BREATHING MACHINE OR VENTILATOR WHEN FACING ADVANCED, LIFE-LIMITING ILLNESS (ALSO REFERRED TO AS INTUBATION)

Are there other ways to relieve the distressing symptoms of shortness of breath and anxiety?

In many cases, medication, such as opiates and tranquilizers and diuretics can be very helpful at providing relief from these symptoms.

If a person with a life-limiting illness elects to use a breathing machine, but later decides that they do not wish to continue or specifies its use for a trial period within their Advance Directives, can the use of the breathing machine be stopped?

Yes, if the patient has indicated this wish through Advance Directives or by communicating wishes with loved ones or with the medical

CPR (CARDIAC PULMONARY RESUSCITATION)—
RESTARTING YOUR HEART is a treatment administered by health care professionals to keep oxygen and blood pumping throughout the body when a person's heartbeat and breathing stop. CPR is used on people in cardiac arrest in order to oxygenate the blood and maintain the pumping action of the heart to keep vital organs alive. The brain may sustain damage after blood flow has been stopped for approximately four minutes and irreversible damage after about seven minutes.

MECHANICAL VENTILATORS (OR BREATHING MACHINES) can be used to support breathing. They can be helpful for critically ill patients who might recover. However, those with a progressive life-limiting illness rarely improve and often become dependent on the breathing machine to keep them alive. Most patients with a life-limiting illness who are placed on breathing machines are unresponsive and rarely have the ability to communicate with their families.

staff. Honoring the patient's wishes to allow a natural death instead of being kept alive artificially on a breathing machine is medically and morally acceptable. If death occurs minutes, hours or even a few days after the breathing machine is removed, death is caused by advanced or progressive illnesses and not the removal of the breathing machine.

SYMPTOM MANAGEMENT AND CONCERNS ABOUT ADDICTION WHEN FACING ADVANCED, LIFE-LIMITING ILLNESS

Most people facing a life-limiting illness want to be comfortable and pain free. Therefore, relief of suffering and maintaining the highest quality of life become the focus of medical care. Controlling symptoms of illnesses often involves the administration of medications for pain, nausea, vomiting, breathing difficulties and other symptoms. As a person's illness progresses, higher doses of these medications are needed to control the symptoms. Increasing the doses often creates a concern for the patient, his family, and healthcare providers, especially if the person is less alert or awake. However, lowering the dosage of these medications can interfere with the goals of symptom management.

Will this cause addiction?

It is normal for dosage requirements to increase as an illness progresses. This is caused by severity of the disease and tolerance to medications and does not mean the patient is addicted. The appropriate dose is the one that adequately controls the patient's symptoms. Numerous studies have shown the risk of addiction is very small when these drugs are used appropriately.

Since many of these drugs cause slower or shallower breathing, will they hasten or speed up death?

Respiratory depression (slowed breathing) occurs less frequently in patients being treated for severe pain, shortness of breath, or anxiety. Relief of these symptoms can actually prolong life by reducing anxiety and improving comfort. Many studies have actually shown that these drugs do not cause death at the end of life, when used appropriately.

Is it ethically appropriate to use such high doses of medications even though there is a small risk of respiratory depression (slowed breathing) or death?

It is ethically appropriate as long as the intent is to treat distressing symptoms in severe life-limiting disease. This differs from euthanasia or assisted suicide, where the intent is to cause someone's death.

Discuss your concerns about all of these practical and ethical considerations with your doctor and spiritual advisor and encourage those close to you to be informed. Misunderstandings can result in painful memories around the death of a loved one.

UNDERSTANDING PALLIATIVE CARE & HOSPICE CARE

When facing a serious or chronic illness, such as Diabetes or Chronic Obstructive Pulmonary Disease (COPD), palliative care may be appropriate. PALLIATIVE CARE is not limited to those facing a life-limiting illness, rather it can supplement more aggressive treatments when they are warranted and can help people with chronic conditions live more comfortably.

HOSPICE CARE is similar to palliative care in that it aims to relieve suffering and improve a patient's quality of life. But unlike palliative care, the patient is predicted to have six months or less to live. In hospice care, the focus shifts to providing comfort since the disease is in late or final stages and a cure is not possible.

Patients, families, and health care providers sometimes have concerns that interfere with a timely referral to hospice care. Some people feel like a referral to hospice means “we’re giving up.” In reality, hospice care focuses on improving the quality of life with symptom relief and supportive care. As a result, patients often live longer and more comfortably than those who are not receiving hospice care.

Referral to hospice **does not eliminate the hope of ever getting better.** If a patient shows signs of improvement from their underlying disease, more aggressive

measures can be used for the patient. In fact, some patients actually “graduate” from hospice.

What types of services does hospice care provide?

Hospice, together with a patient's doctor, helps manage pain and other distressing symptoms such as nausea, diarrhea, shortness of breath and fluid build up. Controlling these symptoms typically allows the person to live more fully and with dignity. Hospice delivers medications and equipment, assists with personal care needs such as baths, and helps with practical matters, such as giving family caregivers a needed break. Hospice may also provide social work services, volunteer visitors, as well as spiritual and grief support. Hospice also includes supportive services to family members and caregivers after the loss of their loved one, such as bereavement counseling.

Who is a part of the hospice care team?

The patient and his or her loved ones are at the center of the hospice team. Patients and caregivers are supported by a team who works to help manage the pain and control the symptoms associated with their illness and to provide personal, respectful care. Hospice team members include:

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HOSPICE CARE focuses on maximizing quality of life, ensuring symptom relief and supportive comfort care. Hospice care also assists the family with important end of life considerations. It is appropriate for someone in the final stages of a life-limiting illness with a life expectancy of 6 months or less.

MEDICAL DIRECTOR: The Director oversees the care plan and consults regularly with other team members. The Medical Director also works with the patient's primary physician.

NURSES: Hospice nurses provide compassionate and skilled nursing care. They work closely with the physician to manage pain and symptoms, individualize patient care, and inform and support the patient's loved ones.

SOCIAL SERVICE PROFESSIONALS: Experienced social service professionals nurture and care for the patients' and families' emotional needs through all stages of the illness. They provide counseling and assistance with a variety of areas including, but not limited to, social and economic needs, advance directives (such as living wills), Medicare/Medicaid and Supplemental Security Income information, and funeral arrangements.

HOME HEALTH AIDES: Home health aides provide personal care and comfort for patients by assisting with cleanliness and the safety and emotional support of the patient.

SPIRITUAL COUNSELOR: Clergy members offer spiritual guidance and support. They assist the patient's minister, rabbi or other spiritual representative in whatever capacity chosen. They also can conduct funeral services, if requested.

VOLUNTEERS: Volunteers are specially screened and trained to provide companionship and assistance to patients during the last stages of their illnesses.

BEREAVEMENT EXPERTS: Hospice may have licensed mental health professionals offering bereavement assistance to survivors following the death of their loved one. Individual and family counseling and support groups are available as well. Support is extended to family members for as long as 13 months after a loss.

How do you enroll & pay for hospice care?

Hospice care does require a referral from a physician, but anyone can make the initial referral to

the program, including the patient, family members, clergy, or a medical care provider. Most people have Medicare, Medicaid or private insurance that covers the cost of hospice services.

What hospice care providers are available in Middle Tennessee?

Ask your doctor, your hospital social worker or case manager, your friends, or online or in AgeWell's *Directory of Services*. For a current copy of the directory, please call the AgeWell office at 615-353-4235 or visit online at www.agewelltn.org. Copies are also available for free at the public libraries in Middle Tennessee.

FINANCIAL & LEGAL ISSUES

FINANCIAL ORGANIZATION & PLANNING AHEAD

Everyone has an estate no matter how small. A financial advisor can help you make a plan that meets your needs. Consider talking to an estate planning attorney, banker, CPA, or a financial planner. It is also good to keep up-to-date records of your assets. You will find an **Essential Records Worksheet** at the back of this booklet that can help you identify and record important financial information.

Let a trusted family member know where to find financial records and other important documents.

IMPORTANT RECORDS TO GATHER

- Sources of income
 - Employment, social security income, pension, investments, and retirement accounts
- Bank account information
 - Where accounts are held
 - Account numbers and name(s) on each account
- Certificates of deposits
 - Interest rates
 - Due dates
- Investments
 - Brokerage accounts
 - Retirement accounts
 - Stock certificates
- Past income tax returns
- Real estate records
 - Mortgage information including reverse mortgage
 - Where to access the deed and how it is titled
 - Insurance policies
- Life insurance policies
- Health insurance policies
- Long-term care insurance policies
- Burial insurance/prepaid funeral planning information

- Any legal documents
- Any business or loan documents
- Other important records
 - Marriage license
 - Military discharge paperwork
 - Social Security Card
 - Death certificate of deceased spouse
 - Automobile titles and registration

LIVING TRUSTS

A living trust takes effect during your lifetime and allows you to earmark assets for heirs while still receiving income or other benefits from the assets. A **revocable** living trust gives you the right to change or cancel trust provisions. It allows an individual to act as trustee and retain lifetime control over trust assets. At his/her death or incapacity, trust management is transferred to a successor trustee. It helps to avoid probate and ensure the continuous management of trust assets and the flow of income in the event of the grantor's death, disability or incapacity. Because the grantor maintains control over trust assets, he/she must pay income tax on those assets. An **irrevocable** living trust means that the trust cannot be changed or terminated. It is usually created to protect assets, reduce taxes and/or transfer assets.

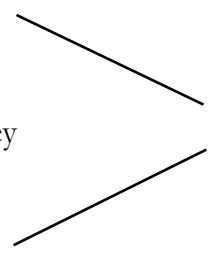
There are other types of trusts that can be set up for different and specific benefits. It is best to consult an attorney or financial professional to assist in exploring your options.

WHAT LEGAL DOCUMENTS ARE NEEDED?

LAST WILL AND TESTAMENT is a legal instrument, declarative of a person's intent to be performed after his/her death with respect to the distribution of property, digital assets, guardianship of any children, and/or administration of his/her estate.

DURABLE POWER OF ATTORNEY is a legal document that authorizes another person (the attorney-in-fact) to act on your behalf to manage financial and business affairs, as well as general decision making (depending on the language of the document). It may only be valid under certain circumstances (such as if you are disabled or mentally incompetent) or it may become effective immediately. It can be very specific about the decisions that the attorney-in-fact is authorized to make or it can be more general.

An APPOINTMENT OF HEALTH CARE AGENT is a document that allows you to name another person to make health care decisions for you in the event that you are unable or too sick to make the decisions for yourself.

- Last Will & Testament
 - Durable Power of Attorney
 - Appointment of Health Care Agent (sometimes called Medical Power of Attorney or Durable Power of Attorney for Health Care)
 - Advance Care Plan or Living Will
 - Advance Directives
- 

A well-drawn LAST WILL & TESTAMENT is essential to make sure that your estate is administered according to your wishes. Without a will, state law and a judge will determine how your assets are distributed. This could cause your heirs to go through difficult public hearings and your estate may have additional legal expenses that you did not intend to occur.

A Last Will & Testament can be used to transfer wealth and address your estate planning objectives. It can help with the fulfillment of your wishes, including specific bequests to individuals or charities and should include your choice of a personal representative who will oversee your estate).

You can appoint someone to help you manage your affairs, including financial matters with a DURABLE POWER OF ATTORNEY. It is important to have this document in place BEFORE you become incapacitated to sign a legal document.

The Durable Power of Attorney covers financial, business, and general decisions, but does not address health care decisions.

You will also need to complete a document called APPOINTMENT OF HEALTH CARE AGENT (or another document that gives legal authority to another person to make health care decisions, like a Durable Power of Attorney for Health Care).

Remember!! Don't confuse the Durable Power of Attorney with the Durable Power of Attorney for Health Care (or Appointment of Health Care Agent). You need to complete both documents to addresses financial/business decisions and the health care decisions, even if you want the same person appointed to both roles.

You can document the care that you want to receive and the medical treatments you are agreeable to within a document called an ADVANCE CARE PLAN (or Living Will). This provides guidelines for your medical team to follow in the event that you are unable to communicate for yourself and you are facing an advanced, life-limiting illness. However, one limitation of the Advance Care Plan is that state law requires emergency personnel

follow a separate directive regarding resuscitation, such as a “Do Not Resuscitate Order (DNR)” or “Physician’s Orders for Scope of Treatment (POST)” form.

These forms must be completed by a physician or other health care professional in certain situations. They are based on a patient’s wishes, best interests and medical indications.

HOW TO OBTAIN COPIES OF THESE FORMS AND COMPLETE THEM:

It is best to seek legal assistance when completing a Last Will and Testament and Durable Power of Attorney. You can contact a local attorney for assistance or, if your income is limited, your local Legal Aid Society is a helpful resource. AgeWell’s *Directory of Services* provides a listing of elder law attorneys, as well as contact information for the Legal Aid Society and several other local resources for legal assistance.

You are NOT required to have an attorney to complete an Advance Care Plan and Appointment of Health Care Agent. You will find a copy of this form on page 33. You can also access copies of Advance Directives by visiting the State of Tennessee website at www.tn.gov/health and search “advance directives.”

ADVANCE CARE PLAN is a document that tells your doctor how you want to be treated if you are terminally ill or permanently unconscious. You can use an Advance Care Plan to tell your doctor you want to avoid life-prolonging interventions and your desire to be pain free and comfortable at the end of life. You can provide any special instructions or limitations you wish.

ADVANCE DIRECTIVES refers to the legal documents that allow you to convey your decisions around end of life care. These documents provide a way for you to communicate your wishes to friends, family, and health care professionals. Advance Directives should include both a document (1) that allows you to make your own end of life wishes known if you are unable to speak for yourself and (2) one that allows you to appoint someone to make medical decisions on your behalf in the event that you are unable or too sick to speak for yourself. Advance Directives include Advance Care Plan/Living Will, DNR/POST Order, Appointment of Health Care Agent/Durable Power of Attorney for Health Care and any other legal document outlining your end of life wishes.

COMMON QUESTIONS ABOUT ADVANCE DIRECTIVES

WHY DO I NEED TO HAVE AN ADVANCE CARE PLAN AND APPOINT A HEALTH CARE AGENT?

Health care professionals are legally obligated to follow your wishes as stated in your Advance Directives. However, you might be in a condition that is not covered in your Advance Directives. If this happens, your Health Care Agent can talk to your health care providers and make treatment decisions in accordance with your wishes. Your Health Care Agent can also make decisions as your medical condition changes, in accordance with your wishes and best interests.

THE ADVANCE DIRECTIVES FORM HAS SOME TERMS I DON'T UNDERSTAND, WHAT SHOULD I DO?

It is best to discuss medical treatments with your doctor. He/she will be able to talk to you about your health situation and the effects that some of the medical treatments might have in your circumstance. You can also refer to the glossary in the back of this book.

WHEN DO MY ADVANCE DIRECTIVES TAKE EFFECT?

Your Advance Directives takes effect when you are terminally ill or facing an irreversible condition and you are unable make decisions about your health care. This judgment is normally made by your physician.

WHAT HAPPENS IF I REGAIN THE ABILITY TO MAKE MY OWN DECISIONS?

The State of TN Advance Directive allows you to select whether your health care agent may act at anytime (even when Principal is competent) OR only when Principal lacks capacity.

WHO SHOULD I APPOINT AS MY AGENT?

Your Health Care Agent is the person you choose to make medical decisions if you become unable to make those decisions yourself. Choose a person who knows you well and whom you trust to make

serious decisions. Your Agent may be a family member or a close friend, **but make sure the person you name clearly understands your wishes and is willing to accept the responsibility of making medical decisions for you.** You will need to revisit this decision regularly and may need to change your health care agent if that person is no longer capable to assume this role. It is also strongly suggested that you appoint a second person as an alternate agent if the first person you name is unable, unwilling, or unavailable to act for you.

MAY I APPOINT TWO OR MORE PEOPLE TO BE MY HEALTH CARE AGENT AT THE SAME TIME?

Yes, however, it is generally not a good idea to appoint two people to simultaneously be one's health care agent. This can lead to confusion and perhaps even disagreement in a time when decisions must be made in a timely fashion. It is best to appoint only one person and to have an alternate in case the appointed agent is unavailable or unable to serve.

SHOULD I DISCUSS MY WISHES WITH MY HEALTH CARE AGENT?

YES! Your Health Care Agent is the person who speaks for you when you can't speak for yourself. It is very important that you talk with your agent and also with your family, friends, and physicians about your Advance Directives. Make sure they understand your wishes regarding medical care and you update them regularly as your health changes.

HOW DO I KNOW THAT MY HEALTH CARE AGENT WILL FOLLOW MY WISHES?

Your Health Care Agent will have the legal authority to make decisions for you. It is important that you select someone who will be comfortable with your decisions and that you can trust to abide by them. Here are some questions your might want to ask the person you are considering for this role:

- Will you seek out information about my illness, advance directives, and what to expect as I near the end of life?
- Will you respect my wants and needs, even if they are different from what you want for yourself?
- If I cannot communicate, will you advocate for me to make sure that what I want is done, even if someone close to me disagrees?

WHAT IF I CHANGE MY MIND?

You may revoke all or part of your Advance Directives at any time so long as you still have mental capacity. This can be done orally or in writing. If you revoke a document, destroy all known copies.

If your spouse is your Health Care Agent, a decree of annulment, divorce, dissolution of marriage, or legal separation revokes his or her power.

An advance directive that conflicts with an earlier advance directive revokes the first directive to the extent of the conflict. It is a good idea to review your directives on a regular basis (we suggest yearly). Remember to notify your family, friends and physicians of any changes you make.

CAN I ADD SPECIFIC INSTRUCTIONS ABOUT MY HEALTH CARE TO MY ADVANCE DIRECTIVES?

One of the strongest reasons for naming an Agent is to have someone who can respond as your medical situation changes and deal with situations that you did not foresee. If you add instructions to this document, it may help your agent carry out your wishes, but be careful that you do not accidentally limit your Agent's authority to act in your best interest.

This is why it is so important once again to discuss future medical care with your doctor, family, and your appointed Health Care Agent. Describe what you consider to be an acceptable “quality of life” and make sure they know what

kinds of treatments you want and do not want in that condition.

You can also add specific instructions about things not covered in the Advance Care Plan form. Commonly, people write instructions regarding organ donation and burial or cremation wishes.

HOW DO I MAKE MY TENNESSEE ADVANCE DIRECTIVES LEGAL?

You must sign your advance directives. Your signature must either be notarized or witnessed by two competent adults (18 years or older, or an emancipated minor).

If you have your signature witnessed, the witnesses cannot be the person you name as your agent.

Also, at least one of your witnesses must be:

1. A person who is **NOT** related to you by blood, marriage, or adoption; and
2. A person who will **NOT** inherit any part of your estate.

WILL MY ADVANCE DIRECTIVES BE HONORED IN ANOTHER STATE?

This may vary from state to state. If you spend a significant amount of time in more than one state, it is best that you complete Advance Directives for all the states involved. However, most states will recognize Advance Directives that are valid in Tennessee.

I HAVE SEEN OTHER VERSIONS OF THE ADVANCE DIRECTIVES FORM OR SIMILAR DOCUMENT--ARE THEY LEGAL?

They may be—consult an attorney to be sure. For example, in 2004, the Tennessee Legislature attempted to simplify the legal documents related to end of life care—resulting in the Advance Care Plan and Appointment of Health Care Agent, but properly executed documents that were more commonly used prior to this change (such as the Durable Power of Attorney and Living Will) are also valid.

I'VE FILLED OUT MY ADVANCE DIRECTIVES... NOW
WHAT?

Advance Directives are important legal documents. Make sure to keep the original signed documents in a secure, but accessible place. Inform your family and loved ones where the documents are kept.

Do not put the original document in a safe deposit box or any other locked box that others cannot access.

Give copies to your appointed Health Care Agent, physicians, family, close friends, clergy, lawyer, or anyone else who might become involved in your healthcare. If you are admitted to a hospital or nursing home, have photocopies of your Advance Directives placed in your medical records.

When you give this document to those people, ask them to read over the paper. Talk with them about anything that may not be clear.

Also, be aware that some Advance Directives documents will not be effective in the event of a medical emergency. Ambulance and hospital ER staff are required to provide CPR unless they are given a separate document that states otherwise. In the State of Tennessee, a physician or other health care professionals may sign a DNR or POST form, if appropriate, that communicates a person should not be resuscitated.

Refer to the Additional Resources chapter for more help with end of life planning.

SPIRITUAL AND CULTURAL CONSIDERATIONS

Near the end of life, it is common to focus on the meaning of life and legacy. You may feel a need to resolve regrets or conflicts in your relationships. Feeling at peace with your life is an important factor in your end of life experience. Many people find that their spiritual, religious, and cultural beliefs help guide them through this journey.

Here are a few questions you might consider as you reflect on the end of your life. For some it is helpful to discuss such matters with a chaplain, clergyperson, spiritual director, pastoral counselor, or cultural healer:

- How do your spiritual, religious, and cultural beliefs impact your view of death and dying?
- How do your beliefs inform your understanding of the human experience and the meaning of illness and suffering?
- What would a peaceful and meaningful death look like to you?
- What fears do you have about death and dying?
- Are there any regrets or conflicts, or relationship concerns that you might like to resolve before you die?
- To whom might you need to say – “Thank you, forgive me, goodbye or I love you?”
- Who would you like to be with you at the end of your life? Have you told them why their presence would be important to you?
- How do your end of life wishes fit with your beliefs and values?
- Have you shared your spiritual, religious, and cultural beliefs about end of life care with your family, friends or physician?
- How might your end of life wishes impact your family?

It is important to discuss your values with everyone around you. Your survivors may have difficulties accepting your wishes or the care that was provided if they do not understand how it aligned with your values.

You may also want to consider the spiritual implications of common end of life issues, if you were faced with a terminal illness:

- The use of life support (breathing machine) to extend life
- Interfering with the natural process of death with medical interventions or artificial nutrition
- Withholding or withdrawing care
- Organ donation

THE ROLE OF SPIRITUAL, RELIGIOUS, AND CULTURAL BELIEFS IN END OF LIFE CARE

You have likely heard the buzz term “interdisciplinary team” within the health care system. This term describes many of the people that may be involved in your healthcare. This team may include chaplains, parish nurses, clergy, cultural healers, and others related to your cultural, spiritual, and religious beliefs. All the members of this team will work together with your medical provider to support your care and assist you with medical and interpersonal challenges. For example, a chaplain may assist you in finding a spiritual exercise that helps with physical pain or nausea. Hospice care emphasizes the use of an interdisciplinary team and the importance of spirituality at end of life, but you can access the support of spiritual care providers outside of hospice care.

Understanding the differences between spiritual care providers:

- Chaplains must have a graduate-level theology degree and are certified by one of five organizations. They must complete a two-year training program called Clinical Pastoral Education (CPE). Chaplains are qualified to work with patients of any religious denomination, as well as those who are not religious or who don’t identify themselves as spiritual.

- Non-chaplain clergy typically provide more religious oriented care, usually with a patient of the same religious denomination.
- Pastoral counselors are mental health counselors with an advanced degree who have additional training in spiritual, existential and religious issues.
- Spiritual directors work with patients to deepen their relationship with the divine power/higher being/transcendent, however the individual patient understands that concept.

Definitions found in “Religion, Spirituality, and End of Life Care” by Puchalski, Droff, Hebbar, and Hendi. May 2012, updated June 11, 2012.

HOW TO SHARE YOUR END OF LIFE DECISIONS WITH OTHERS

Once you have considered your wishes about end of life care and completed Advance Directives, the next step is to share your wishes with those you love. Studies have shown that families are often unaware of their loved one's wishes. This is not surprising because most people find it difficult to talk about illness, death, or losing someone they care about. Even so, it is very important to share this information with your family and physician, and especially the person you appoint as your Health Care Agent.

WHAT TO DISCUSS

No one knows the exact circumstances that will unfold at the end of life, so it is important to have a general conversation about your wishes, beliefs, and values. This will give your loved ones a framework for how you want to be treated near end of life and give them a sense of peace when making difficult decisions.

You may want to review your answers to the questions raised in the first section of this booklet, such as:

- Where do you prefer to receive care?
- How important is independence to you?
- What are your fears and beliefs around death and dying?
- Where do you prefer to die—at home, at the hospital, at a hospice facility?
- Do you wish to enlist hospice care?
- Do you have any specific convictions about being resuscitated or the use of artificial nutrition?

If you complete Advance Directives, you can use them to guide your conversation. Be sure to provide your reasons for your decisions so that your loved ones have a better understanding of your values.

Give specific guidance when possible. In compiling this booklet, health care professionals shared that the three hardest decisions for family members are about 1) whether or not to restart someone's heart (resuscitate); 2) whether or not to use a breathing machine (intubate) 3) whether or not to provide artificial hydration and nutrition through a feeding tube or IV. Be sure to address these issues so that your health care agent and loved ones feel knowledgeable about your wishes.

HOW TO START THE CONVERSATION

Starting the conversation can feel awkward for both you and your loved ones. Try using the following opportunities for having the conversation:

- Around significant life events, such as marriage, birth of a child, death of a loved one, retirement, birthdays, or anniversaries
- While drawing up a will or doing other estate planning
- When major illness requires that you or a family member move out of your home and into a retirement community, nursing home, or other long-term care setting
- During holiday gatherings, such as Thanksgiving, when family members are present
- When a friend or another family member is facing illness or passes away

Here are a few ways to start the conversation:

- "I'd like to talk to you about what would happen if I got really sick."
- "I want to share my wishes about how I'd like to be cared for if I am sick or injured."

End either of these statements with a comment like- "it's important to me that I share my wishes in the event that I can not speak for myself."

You could also start a conversation with someone you love about their wishes and use this opportunity

for both of you to discuss end of life care:

- “I’d like to talk about the best way someone might care for you if you got really sick.”
- “If you ever got sick, I would be afraid of not knowing the kind of care you would like.”

Another way to start the conversation is to share an article or story about the topic with your loved one. If you or your loved one is very uncomfortable with the conversation, you could start by writing your wishes in a letter and then follow it up by talking about it. However, it is important to have the person read the letter right away because they may not have time to get the letter if a crisis happens.

You could also seek a professional to help you and your family with this conversation, such as a counselor, social worker, attorney, clergy or spiritual healer.

WHAT TO DO IF FAMILY MEMBERS DISAGREE

To ensure that your wishes will be followed, consider whether the person you are appointing as your Health Care Agent will be comfortable with and will abide by your wishes. Your Agent has the legal right to make decisions for you even if close family members disagree. Should close family members express strong disagreement with your wishes, your Health Care Agent and doctor may find it extremely difficult to carry out the decisions you want.

If you foresee that disagreement may occur between family members, the following steps may help:

- Communicate with all family members and address any objections they might have to your decisions.
- Tell them in writing who will act as your Health Care Agent and explain why you have appointed that person. Include who is the primary and

who is the alternate decision maker.

- If there are persons you do NOT want involved with decisions about your medical care, put that in writing and provide that information to your Health Care Agent and doctor. You can also include those instructions in your Advance Care Plan.
- Seek the assistance of professionals when needed.

HOW TO TALK TO YOUR DOCTOR

It is also important to talk to your doctor about your end of life wishes before a crisis occurs. Here are some suggestions of what to discuss:

- Ask your doctor about any medical treatments or terms that are confusing to you.
- Ask your doctor about palliative and hospice care.
- Ask your doctor if he/she is willing to follow your wishes. (The law does not force doctors to follow directives they disagree with for moral or ethical reasons.)
- Discuss your wishes and who you are appointing your Health Care Agent. (This would be a great time to provide a copy of your Advance Directives.)

CONVERSATIONS NEAR END OF LIFE

If you are facing a terminal illness, it’s important to remember that family members may want and need to help. Try to put away concerns about being a burden and let them be present for you. If you are a family member, remember that the person facing the end of life may need to talk about dying and what happens to family and belongings when they’re gone. Try not to say things like “don’t talk like that...” It’s important to let the person talk about what’s on his/her mind. Sometimes your loved one may need to hear that you will be okay after they are gone.

FUNERAL PLANNING

Thinking ahead can help you make informed and thoughtful decisions about funeral arrangements. It allows you to leave instructions for how you want your friends and family to celebrate your life. It also spares caregivers the stress of making these decisions under the pressure of time and emotions. Arrangements can be made directly with a funeral establishment or through a funeral planning or memorial society. Many people prepay some or all of the expenses involved, such as with a PRE-PLAN OR PRE-NEED contract.

THERE ARE SEVERAL METHODS AVAILABLE TO PRE-PAY FOR A FUNERAL:

Before making a decision consider these options with an attorney, financial planner or other trusted advisor.

- A regulated trust can be established by a licensed funeral director.
- A life-insurance policy can be purchased, equal to the value of the funeral.
- Individuals can establish a savings or certificate of deposit account earmarked for funeral expenses. The account can be designated as “payable on death” (POD) to the funeral home.

EACH METHOD HAS ITS ADVANTAGES. TO HELP DETERMINE WHICH OPTION IS BEST FOR YOU, MAKE SURE TO ASK YOUR FUNERAL DIRECTOR THE

FOLLOWING QUESTIONS:

- Who receives the interest on the account?
- Who must pay taxes on the interest?
- Is the prepayment ever refundable, in part or in full?
- Can the plan be used at a funeral home of your choice?
- What happens if the funeral home goes out of business or is sold?
- What is included in pre-need? Merchandise like a casket and vault or funeral services or both?
- In the event that you move, is the prefunded plan transferable?

OTHER CONSIDERATIONS:

- Funeral homes must disclose the cost of all goods and services and, upon request, provide a written price list for your review.
- Organ and body donations must also be preplanned during the person’s lifetime.
- Plans should be placed in writing and kept where they can be easily found by family members. It is important that family members be told that such plans exist and where to find related documents.
- The Social Security Administration, the Veterans Administration and life and casualty insurance companies pay death benefits. Call these

A PRE-PLAN OR PRE-NEED is a contract that outlines funeral services to be rendered in the future, that are partially or fully paid for now. It could be payment made directly to the funeral home or the purchase of an insurance policy that will cover the cost of the funeral. Most funeral preplans are based on today’s cost for funeral services.

- agencies to determine coverage and benefits.
- The Veterans Administration offers many benefits for honorably discharged veterans. Veterans and their spouses and children may be buried in veterans' cemeteries. Veterans may receive money for a private burial and a headstone at no charge. Information on veterans' benefits can be obtained online at www.va.gov.

Learn more about your rights as you preplan your funeral arrangements by visiting National Funeral Directors Association website at www.nfda.org.

DECISIONS YOU WILL NEED TO CONSIDER AS YOU PREPLAN YOUR FUNERAL:

Make plans ahead of time to choose burial plot, columbarium or mausoleum. You will also want to ensure that you have made arrangements for how your body is cared for, especially if there are special considerations that may be necessary for your religious/spiritual beliefs. You can also make specific plans about your selection of caskets, vaults, urns.

Often times funeral home representatives will give you a workbook that will allow you to write down information about your final wishes. This is where you can make choices about your music selections, special prayers or readings, flowers, clothing, pallbearers, published obituary, or any other selections that may be important to you.

There are also preplanning packages available for those who wish to be cremated.

GRIEF & LOSS

It is normal to feel emotional pain, or GRIEF, when facing your own illness and death or that of a loved one. It requires that we labor through the emotional storm of realizing loss, of saying goodbye, of being angry and alone, and finally of learning to live with a new reality.

In the face of loss you may experience:

- Shock/confusion
- Panic/crying spells
- Anger/guilt/relief
- Appetite or sleep disturbances
- Aimlessness

Though each of us experiences loss in our own unique way, there are similarities in this complex experience, and there are supports to help us through this journey.

Healing begins when you:

- Are patient with yourself
- Share your feelings
- Pay attention to your physical needs
- Learn more about grief and its effects
- Ask for help when needed

MANIFESTATIONS OF NORMAL GRIEF

Normal grief is not just sadness or depression. It reaches into every part of your life and touches your work, your relationships with others, and your self image. You can expect grief to affect your

feelings and your ability to think clearly. Grief may even produce unusual physical sensations and behaviors.

FEELINGS

- Sadness – often through crying
- Anger – sense of frustration at not being able to prevent death
- Guilt and self-reproach
- Anxiety – from insecurity to panic attack
- Loneliness
- Fatigue – apathy or listlessness
- Helplessness – akin to anxiety
- Shock – immediately after death, especially sudden death
- Yearning/pining
- Relief – death after a lingering illness (often accompanied by guilt)
- Numbness – nature’s way of anesthetizing survivors immediately after death

PHYSICAL SENSATIONS

- Hollowness in the stomach
- Over-sensitivity to noise
- Breathlessness, feeling short of breath
- Lack of energy
- Tightness in chest or throat
- Sense of depersonalization
- Weakness in the muscles
- Dry mouth

THOUGHT PATTERNS

- Disbelief – “It didn’t happen.”; “I’ll wake up and find it was a dream.”
- Confusion – difficulty

GRIEF is a reaction to a loss, mainly associated with sadness and emotional pain, but it can also result in physical reactions. Grief is not only the reaction to the death of a loved one; rather it encompasses the response to all forms of loss in one’s life, such as the loss of health, friendship, or employment.

- remembering or concentrating
- Preoccupation – intrusive thoughts or images of the dead person
- Sense of presence – deceased is somehow in your current time and space
- Hallucinations – both visual and auditory

BEHAVIORS

- Sleep disturbances – difficulty going to sleep or early morning awakening
- Appetite disturbances – more frequently under-eating, but also overeating
- Absent-mindedness – doing atypical or potentially harmful things
- Social withdrawal – loss of interest in outside world
- Dreams of the deceased – usually reassuring
- Avoiding reminders of the deceased – avoidance of grief triggers
- Searching and calling out – may or may not be verbalized
- Sighing – similar to breathlessness
- Restless over activity – avoiding thoughts and situations
- Crying – liquid emotion
- Carrying reminders of the deceased – pictures or items for security
- Treasuring objects of the deceased – wearing clothes or carrying amulets

REACHING OUT FOR HELP

Grief counselors and support groups offer the opportunity to share our feelings and stories with others, and help us recognize that we are not alone. There are several agencies that a grieving loved one can access for counseling and assistance through the grief process. This assistance is accomplished in individual and group settings with adults, children, preteens, teens, families, and friends. Some grief counseling agencies are free, and others have a fee. Your faith community may also have experience in helping with grief.

Grief counselors and support groups can be found through:

- Hospice
- Some funeral homes
- Your Church/Congregation
- Community Center
- Organizations related to one's illness (Such as the Alzheimer's Association or the American Cancer Society)

AgeWell's *Directory of Services* lists hospice agencies as well as organizations related to one's illness. Call for a copy or visit www.agewelltn.org.

ADDITIONAL RESOURCES

AGEWELL MIDDLE TENNESSEE'S DIRECTORY OF SERVICES. Visit AgeWell Middle Tennessee (3511 Belmont Blvd. Nashville, TN 37215) or your local library branch to pick-up a copy (free to older adults and caregivers). You can access the directory online on our website at www.agewelltn.org, under the resources option. AgeWell Middle Tennessee has a free tool to assist you in end of life planning. Visit: <https://app.lifelegacy.io/wills?partner=agewelltn>

LEGAL AID SOCIETY OF MIDDLE TENNESSEE'S ADVANCE HEALTH CARE PLAN GUIDE & DOCUMENT: Their website has brief booklet that explains the Advance Health Care Plan (Living Will) as well as a form. For additional information, please visit www.las.org and click on "Legal Help Booklets".

AGING WITH DIGNITY'S FIVE WISHES: Five Wishes lets your family and doctors know:

- Who you want to make health care decisions for you when you can't make them.
- The kind of medical treatment you want or don't want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

www.fivewishes.org

AARP-END OF LIFE CARE: Articles, videos, and resources to assist you in making end of life care decisions, support caregivers, and help those facing a terminal illness. www.aarp.org/caregiving/basics

PUT IT IN WRITING CAMPAIGN: A program of the American Hospital Association, "Put It in Writing" provides basic facts about advance directives and encourages patients to explore their preferences for care at the end of life. Also offers a Wallet ID card with Advance Directives information. www.aha.org/2017-12-11-put-it-writing

CARING CONNECTIONS: Access each state's specific Advance Directive forms and learn about caring for a terminally ill loved one, how to live with terminal illness, grief, and hospice care. www.caringinfo.org

CONSUMER'S TOOL KIT FOR HEALTH CARE ADVANCE PLANNING: A program of the American Bar Association that contains a variety of self-help worksheets, suggestions and resources that prompt a continuing conversation about values, priorities, and the meaning of one's life, and quality of life. www.americanbar.org/groups/law_aging/publications

THE CONVERSATION PROJECT: A project dedicated to helping people talk about their end of life wishes. www.theconversationproject.org

GLOSSARY OF TERMS

ADVANCE CARE PLAN is a document that tells your doctor how you want to be treated if you are terminally ill or permanently unconscious. You can use an Advance Care Plan to tell your doctor you want to avoid life-prolonging interventions and your desire to be pain free and comfortable at the end of life. You can provide any special instructions or limitations you wish.

ADVANCE DIRECTIVES refers to the legal documents that allow you to convey your decisions around end of life care. These documents provide a way for you to communicate your wishes to friends, family, and health care professionals. Advance Directives should include both a document that allows you to (1) make your own end of life wishes known if you are unable to speak for yourself and (2) one that allows you to appoint someone to make medical decisions on your behalf in the event that you are unable or too sick to speak for yourself. In Tennessee, Advance Directives may refer to the Advance Care Plan/Living Will, Appointment of Health Care Agent, or Durable Power of Attorney for Health Care. (Learn more in the Financial & Legal Issues Chapter).

APPOINTMENT OF HEALTH CARE AGENT is a document that allows you to name another person to make health care decisions for you in the event that you are unable or too sick to make the decisions for yourself.

ARTIFICIALLY PROVIDED FLUIDS AND NUTRITION is a method of providing food and water to seriously ill patients who are unable or unwilling to eat. Fluids and nutrition can be given through an IV, or a Nasogastric (NG) tube, which goes through the nose, down the throat and into the stomach. Sometimes the NG tube is called a Dobhoff tube. Unfortunately, both of these methods can only be used temporarily because of the complications that develop if they are used too long. The only

permanent feeding tube is a PEG (permanent endoscopic gastrostomy), which goes straight through the abdomen and into the stomach. A PEG tube involves minor surgery. All these methods typically involve continuous supervision by medical staff and present the risk of injury or infection and other adverse effects.

CPR (CARDIAC PULMONARY RESUSCITATION)—RESTARTING YOUR HEART is a treatment administered by health care professionals to keep oxygen and blood pumping throughout the body when a person's heartbeat and breathing stops. CPR is used on people in cardiac arrest in order to oxygenate the blood and maintain the pumping action of the heart to keep vital organs alive. The brain may sustain damage after blood flow has been stopped for approximately four minutes and irreversible damage after about seven minutes.

DURABLE POWER OF ATTORNEY is a legal document that authorizes another person (the attorney-in-fact) to act on your behalf to manage financial and business affairs, as well as general decision making (depending on the language of the document). It may only be valid under certain circumstances (such as if you are disabled or mentally incompetent) or it may become effective immediately. It can be very specific about the decisions that the attorney-in-fact is authorized to make or it can be more general.

END OF LIFE CARE is the term used to describe the support and medical care given during the time surrounding death, whether from a sudden illness, a life-ending disease or old age.

GRIEF is a reaction to a loss, mainly associated with sadness and emotional pain, but it can also result in physical reactions. Grief is not only the reaction to the death of a loved one; rather it encompasses the response to all forms of loss in one's life, such as the loss of health, friendship, or employment.

HOSPICE CARE focuses on maximizing quality of life, ensuring symptom relief and supportive comfort care. Hospice care also assists the family with important end of life considerations. It is appropriate for someone in the final stages of a life-limiting illness with a life expectancy of 6 months or less.

LAST WILL AND TESTAMENT is a legal instrument, declarative of a person's intent to be performed after his/her death with respect to the distribution of property, guardianship of any children, and/or administration of his/her estate.

LIFE-LIMITING ILLNESS is a chronic disease or condition that doesn't respond to curative treatments, leading to a terminal diagnosis.

MECHANICAL VENTILATORS (OR BREATHING MACHINES) can be used to support breathing. They can be helpful for critically ill patients who might recover. However, those with a progressive life-limiting illness rarely improve and often become dependent on the breathing machine to keep them alive. Most patients with a life-limiting illness who are placed on breathing machines are unresponsive and rarely have the ability to communicate with their families.

PALLIATIVE CARE is a treatment approach that aims to improve the quality of life of people facing serious or chronic illness. It concentrates on pain and symptom management, communication, and coordination of the patient's care. It is NOT hospice care and is appropriate during any stage of an illness.

A PRE-PLAN OR PRE-NEED is a contract that outlines funeral services to be rendered in the future, that are partially or fully paid for now. It could be payment made directly to the funeral home or the purchase of an insurance policy that will cover the cost of the funeral. Most funeral preplans are based on today's cost for funeral services.

FORMS & WORKSHEETS

ADVANCE DIRECTIVE FOR HEALTH CARE*
(Tennessee)

Instructions: Parts 1 and 2 may be used together or independently. Please mark out/void any unused part(s). Part 5, Block A or Block B must be completed for all uses.

I, _____, hereby give these advance instructions on how I want to be treated by my doctors and other health care providers when I can no longer make those treatment decisions myself.

Part 1 Agent: I want the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below:

Name: _____ Relation: _____ Home Phone: _____ Work Phone: _____
Address: _____ Mobile Phone: _____ Other Phone: _____

Alternate Agent: If the person named above is unable or unwilling to make health care decisions for me, I appoint as alternate the following person to make health care decisions for me. This includes any health care decision I could have made for myself if able, except that my agent must follow my instructions below:

Name: _____ Relation: _____ Home Phone: _____ Work Phone: _____
Address: _____ Mobile Phone: _____ Other Phone: _____

My agent is also my personal representative for purposes of federal and state privacy laws, including HIPAA.

When Effective (mark one): I give my agent permission to make health care decisions for me at any time, even if I have capacity to make decisions for myself. I do not give such permission (this form applies only when I no longer have capacity).

Part 2 Indicate Your Wishes for Quality of Life: By marking “yes” below, I have indicated conditions I would be willing to live with if given adequate comfort care and pain management. By marking “no” below, I have indicated conditions I would not be willing to live with (that to me would create an **unacceptable** quality of life).

<input type="checkbox"/> Yes	<input type="checkbox"/> No	Permanent Unconscious Condition: I become totally unaware of people or surroundings with little chance of ever waking up from the coma.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	Permanent Confusion: I become unable to remember, understand, or make decisions. I do not recognize loved ones or cannot have a clear conversation with them.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	Dependent in all Activities of Daily Living: I am no longer able to talk or communicate clearly or move by myself. I depend on others for feeding, bathing, dressing, and walking. Rehabilitation or any other restorative treatment will not help.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	End-Stage Illnesses: I have an illness that has reached its final stages in spite of full treatment. Examples: Widespread cancer that no longer responds to treatment; chronic and/or damaged heart and lungs, where oxygen is needed most of the time and activities are limited due to the feeling of suffocation.

Indicate Your Wishes for Treatment: If my quality of life becomes unacceptable to me (as indicated by one or more of the conditions marked “no” above) and my condition is irreversible (that is, it will not improve), I direct that medically appropriate treatment be provided as follows. By marking “yes” below, I have indicated treatment I want. By marking “no” below, I have indicated treatment I **do not want**.

<input type="checkbox"/> Yes	<input type="checkbox"/> No	CPR (Cardiopulmonary Resuscitation): To make the heart beat again and restore breathing after it has stopped. Usually this involves electric shock, chest compressions, and breathing assistance.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	Life Support / Other Artificial Support: Continuous use of breathing machine, IV fluids, medications, and other equipment that helps the lungs, heart, kidneys, and other organs to continue to work.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	Treatment of New Conditions: Use of surgery, blood transfusions, or antibiotics that will deal with a new condition but will not help the main illness.
<input type="checkbox"/> Yes	<input type="checkbox"/> No	Tube feeding/IV fluids: Use of tubes to deliver food and water to a patient’s stomach or use of IV fluids into a vein, which would include artificially delivered nutrition and hydration.

PLEASE SIGN ON PAGE 2

Page 1 of 2

Part 3 Other instructions, such as hospice care, burial arrangements, etc.: _____

(Attach additional pages if necessary)

Part 4 Organ donation: Upon my death, I wish to make the following anatomical gift for purposes of transplantation, research, and/or education (mark one):

- Any organ/tissue My entire body Only the following organs/tissues: _____
- No organ/tissue donation

SIGNATURE

Part 5 Your signature must **either** be witnessed by two competent adults (“Block A”) **or** by a notary public (“Block B”).

Signature: _____ Date: _____
(Patient)

Block A Neither witness may be the person you appointed as your agent or alternate, and at least one of the witnesses must be someone who is not related to you or entitled to any part of your estate.

Witnesses:

1. I am a competent adult who is not named as the agent. I witnessed the patient’s signature on this form. _____
Signature of witness number 1
2. I am a competent adult who is not named as the agent. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient’s estate upon his or her death under any existing will or codicil or by operation of law. I witnessed the patient’s signature on this form. _____
Signature of witness number 2

Block B You may choose to have your signature witnessed by a notary public instead of the witnesses described in Block A.

STATE OF TENNESSEE
COUNTY OF _____

I am a Notary Public in and for the State and County named above. The person who signed this instrument is personally known to me (or proved to me on the basis of satisfactory evidence) to be the person who signed as the “patient.” The patient personally appeared before me and signed above or acknowledged the signature above as his or her own. I declare under penalty of perjury that the patient appears to be of sound mind and under no duress, fraud, or undue influence.

My commission expires: _____
Signature of Notary Public

WHAT TO DO WITH THIS ADVANCE DIRECTIVE: (1) provide a copy to your physician(s); (2) keep a copy in your personal files where it is accessible to others; (3) tell your closest relatives and friends what is in the document; (4) provide a copy to the person(s) you named as your health care agent.

* This form replaces the old forms for durable power of attorney for health care, living will, appointment of agent, and advance care plan, and eliminates the need for any of those documents.

**APPOINTMENT OF HEALTH CARE AGENT FOR
(TENNESSEE)**

(print or type name of patient)

If I become unable to make or communicate decisions for myself, it is up to my Health Care Agent to communicate my health care wishes and to see that my legal rights are protected. While there may be others who wish to be involved in my care, I want my Agent to have the final say on any & all health care decisions, including:

- Decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my condition;
- Decisions to provide, withhold or withdraw life-sustaining treatments, including artificially provided nutrition and hydration, &;
- Decisions regarding organ donation, burial arrangements, cremation, and autopsy.

I remind my Agent of the responsibility to honor any other advance directives that I've completed and to follow any additional instructions I have left. If my Primary Agent is either unavailable or unwilling to serve, I would like my Alternate Agent named below to make these health care decisions for me. (Note: you do not have to name an Alternate Agent.)

NOTE: If there are any decisions that you do **not** want your Health Care Agent to make for you, or if you have any additional instructions for your Health Care Agent, please list them on the back of this form.

Check here if you have added additional instructions.

Primary Agent:

Alternate Agent (optional):

Name (print)

Name (print)

Address

Address

City State Zip Code

City State Zip Code

(_____) _____
Area Code Home Phone Number

(_____) _____
Area Code Home Phone Number

(_____) _____
Area Code Work/Cell Phone Number

(_____) _____
Area Code Work/Cell Phone Number

Patient's name (please print or type) / Date

Signature of patient (must be at least 18 or emancipated minor) / Date

To be legally valid, you must complete either Block A or Block B below

Block A Witnesses (TWO witnesses required)

1. I am a competent adult who is not named above. I witnessed the patient's signature on this form.

Signature of witness number 1 Date

2. I am a competent adult who is not named above. I am not related to the patient by blood, marriage, or adoption and I would not be entitled to any portion of the patient's estate upon his/her death. I witnessed the patient signature on this form.

Signature of witness number 2 Date

Block B Notarization

STATE OF TENNESSEE COUNTY OF _____

I am a Notary Public in and for the State and County named above. The person who signed this instrument is personally known to me (or proved to me on the basis of satisfactory evidence) to be the person whose name is shown above as the "patient." The patient personally appeared before me and signed above or acknowledged the signature above as his or her own. I declare under penalty of perjury that the patient appears to be of sound mind and under no duress, fraud, or undue influence.

My commission expires: _____

Signature of Notary Public

ESSENTIAL RECORDS WORKSHEET

The following is a suggested listing of important data. This is confidential information and must be safeguarded and shared only with those in whom you have complete trust. Update this information regularly. You will also find helpful information for your survivors (FYI), throughout this record.

Personal Records

Full legal name _____

Religious name (if specified) _____

Home address _____

Phone _____ Cell _____

Birth place and date _____

Birth Certificate, Naturalization Papers location _____

Parents: Mother's maiden and first name _____

Father's full name _____

Driver license number _____ State _____

Social Security number _____

Spouse/Partner _____

Contact information _____

Marriage date and place _____

Divorce date and place _____

Marriage, divorce certificate location _____

Siblings (name and contact information) _____

Children (name and Social Security number, location of birth certificate, contact information)

Grandchildren (children of, name & contact information if different from child's)

Military service history (years and branch of service) _____

Retirement/discharge date _____ Place _____

VA claim # _____ Service serial # _____

Employment / Workplace _____

Address _____

Phone _____

Last/Current Position _____

Years of employment _____ Date of retirement _____

Pension or retirement plan _____

Assets, Financial Interests, And Valuables

Indicate account and institution location

Bank _____

Branch _____

Address _____

Phone _____

FYI: In some states, survivor may withdraw funds from an account only if the account is established with rights of survivorship.

Account	Name on account	Institution/branch	Account number
Savings Account			
Debit Account			
Money Market			
Certificate of Deposit			
IRA			
Annuity Fund			
Pension Fund			
Credit Union			
Other			

Monthly scheduled automatic deductions / additions

Payments	Amount added/ deducted	Institution/ Account accessed	Contact information	Date added/ deducted
Social Security				
IRA				
Pension				
Other				
Deductions				
Mortgage/Rent				
Loans				
Insurance				
Other				

Reoccurring payments debited from accounts (include amount, day of the month, business contact)

Location and number of bank safe deposit box _____

Location of key or lock combination _____

FYI: A bank safe deposit box may be opened only by an authorized signer with a key. If no cosigner for the box is known, the executor of the estate will need to present Letters of Testamentary (or Letters of Administration) and the box may be opened in presence of a bank or safe deposit company authorized employee. Check with establishment to determine their policy on sealing a box once an obituary notice has been published.

Location of valuables or a safe within the home

Location of key(s) or combination(s) _____

Trusts _____

Jointly owned real property:

Address of property _____

Location of deed _____

Real property not held jointly: (subject to probate)

Address of property _____

Location of deed _____

Title to automobile, registration, payment plan _____

Leasing contract information _____

Storage locker/Warehouse location _____

Key location or lock combination _____

When is rent due? Lease expiration? _____

Stock and investments

Financial Advisor or Broker _____

Contact name and address _____

Phone _____

Account number _____

Charge/Credit Account Information: (Name of Card, Account number, Address and phone of company)

Issuer of card	Name on account	Account number	Address of issuer	Phone number

Reoccurring payments debited from credit card accounts (include amount, day of the month, business contact)

Utility companies:

- 1. Gas
- 2. Electric
- 3. Water
- 4. Telephone/Cell Phone
- 5. Cable TV/ Internet Service

FYI: Advise to change billing name if it previously was in name of deceased

Insurance and Legal

Insurance Agent _____
 Company _____
 Address _____
 Phone _____

Life Insurance Policy: Insurer, beneficiary amount, agent and contact information (if payable to beneficiary other than estate)

Insurance company	Policy type, number	Beneficiary	Amount	Agent	Contact information

Additional insurance policies (medical in next section): agent, company, policy #, and contact information.

Home/Rental _____

 Umbrella _____

 Auto _____

Name of Tax preparer/Advisor _____ Phone _____
 Address _____
 Where tax records are kept _____

Lawyer/Attorney

Name _____ Phone _____

Address _____

Have you completed a

____ Last Will and Testament

____ Advance Directives/Living will

____ Appointment of Health Care Agent/Durable Power of Attorney for Health Care:

____ Durable Power of Attorney

____ Other: _____

____ Other: _____

Where are important legal documents kept? _____

Medical

Name and address of physicians/ health care providers/dentist/optician/audiologist/other

Primary Care Doctor _____ Phone _____

Address: _____

Other _____ Phone _____

Address _____

Other _____ Phone _____

Address _____

Medicare # _____

Health Insurance Company and plan _____

Policy # _____ Group # _____

Name of policy holder _____ Relationship _____

Address _____ Phone _____

Perscription drug plan, number _____

Disability Insurance _____

Pharmacy _____

Address _____ Phone _____

Rental of medical equipement _____

Home Health Agency _____ Phone _____
Caregivers _____

Funeral Planning

Spiritual/Religious tradition or affiliation _____

Minister/Rabbi/Spiritual Leader _____

Church/Synagogue/Place of Worship _____

Address _____ Phone _____

I request that I _____ be buried
_____ be cremated
_____ have my body donated to medical science
_____ have my organs donated (special instructions: _____)
_____ ash remains given to _____

I would _____ like the service to be held at the funeral home

_____ like the service to be at my place of worship

_____ like to have only a graveside service

I would like for the services to be _____ public _____ private

I _____ would _____ would not like flowers
(if option is for flowers, I prefer they be _____)

I would like donations in my memory be made to _____

If buried, I would like to be buried in this clothing: _____

I would like to be buried with (jewelry, favorite possession, etc) _____

I would like my remains interred in _____ wooden casket
_____ other as specified _____

Grave marker _____ stone _____ bronze
Decoration as specified _____
Inscription to read _____

Gravesite

_____ Family plot located _____

_____ Family tomb located _____

_____ Previously purchased gravesite located _____

Persons I would like involved in my services and their role (pallbearers, eulogists, etc.):

Other wishes and specific instructions for the service (readings, hymns, music, etc.)

Obituary text or preferred details of life:

People to Notify of My Passing

1. Clergy/Spiritual Leader _____
Phone _____

FYI: Clergy are helpful to the family when a death occurs. When a cemetery plot is situated within a church/synagogue cemetery, notify them to arrange for preparation of the site. (See Funeral Planning section for additional instructions)

2. Funeral Director _____ Phone _____

FYI: Services vary but may include: funeral parlor rental space, flowers, assistance in obtaining death certificates, placing newspaper notices, transportation, clergy services, etc. Costs reflect services and purchased or rented materials.

3. Attorney _____ Phone _____

FYI: Good legal advice is critical. If you do not have a family attorney, the local Bar Association can offer recommendations. An attorney may give legal advice on trusts, recording deeds to real property, conservation and disbursement of estate assets and revising or preparing a will for survivor. The attorney may be able to complete the estate tax return and inheritance tax return. Consider having the attorney's fee established prior to filing the will for Probate. The executor of the estate probates the will with legal advice from the attorney. If there is no will, the court will appoint an administrator for the estate. The executor and the attorney usually go to the Probate Court within one month of the person's death. Probate is a civil proceeding establishing the will, marshalling and protecting the decedent's assets and settling the estate. The role of a Probate Court is generally understood to include the power to authenticate or establish a will and distribute decedent's property. The attorney will need the following data :

1. The decedent's full name, address and date of death
2. Name and address of all decedent's heirs
3. Original (or copy of) will
4. Listing of assets and debts of the estate

4. Accountant _____ Phone _____

FYI: An accountant may assist the executor or survivor by preparing and interpreting financial records and by providing tax information. This person may be able to prepare the estate and inheritance taxes.

5. Executor/Executrix of will _____
Phone _____

6. Life Insurance Agent _____ Phone _____

FYI: Promptly notify agent to discuss payment of benefits. Most companies offer options for payment in various periods of time in various amounts. Unless there is immediate need for all of the cash in a lump sum, other payout options should be considered. In order to avoid rushing into financial decisions immediately, the survivor can ask the insurer to pay out "X" amount for immediate needs and the agency is to keep the rest of the amount to be withdrawn at any time with the interest to begin immediately, and the right to select any settlement option- including a lump sum payout at a later date. The agent should explain all options (and costs) offered by the agency.

7. Bank Trust Office _____
Phone _____

FYI: The bank trust office must be notified if a trust has been established. This officer will review the client's financial value (real estate, securities, cash, personal effects, automobiles, valuables, insurances.) The trust invests funds, collects income from investments, remits income and attends to details involved in handling the trust. The agent will keep financial records and provide the family with required reports. If a trust has not been established, the survivor can arrange for establishment of a trust benefiting the children or a living trust for the survivor's own benefit. Fees charged for this service are set by the bank and are stated in advance.

8. Social Security Administration _____ 1-800-772-1213 _____

FYI: Social Security automatic-deposit benefits cease when the individual is no longer living. The Social Security Agency must be notified by email, phone (1-800-772-1213) or in writing when a death occurs. There may be death/funeral benefits. Do not cash any SSA checks issued in name of deceased. The agency will indicate forms to be submitted or completed.

Social Security survivor or burial benefits are not automatic: one must apply for them. The following information must be supplied in application process:

1. Decedent's Social Security number
2. Record of decedent's earnings in current and previous year.
3. Copy of marriage certificate and any prior divorce decrees for either the decedent or the survivor.
4. Proof of the survivor's age and ages of dependent children.

9. Veterans Administration _____ 1-800-827-1000 or www.va.gov _____

FYI: The Veterans Administration (V.A.) benefits will vary according to the nature of the veteran's death. Contact the US Dept. of Veterans Affairs 1-800- 827-1000. There may be death/burial benefits available. The V.A. may require the following documents to process a claim:

1. Form DD214 (discharge papers) Report of Separation from Active Service. Copy of honorable discharge can be obtained from the National Personnel Record Center, 9700 Page Avenue, St Louis, Mo. 63132 or online at www.va.gov.
2. Certified copy of death certificate
3. Copy of marriage certificate and any prior divorce decrees for either the veteran or the survivor
4. Copy of birth verification for dependent children.

In addition, the veteran's complete name and Government Life Insurance Policy or V.A. claim number should be supplied. The V.A. representative can assist in obtaining the necessary documents if they cannot be located.

10. Relatives and close friends _____

11. Employer, staff, and others _____

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