# Advance Care Planning

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

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# How to Use This Workbook

This workbook is to help you think about the types of care that you would like to receive at every stage of treatment. It provides information and activities to help you understand key topics related to advance care planning. It is also a guide to help you through important questions and conversations.

The sections in this workbook include different advance care planning topics. You may complete the sections in any order.

Parts of advance care planning can be challenging. If you face challenges, consider the following tips to help you.

- Take a break. Take your time working through this workbook. Put it down and go for a walk. Write about your thoughts and feelings in a journal. Sleep on it.
- Communicate openly with the people you trust and who care about you. Let them support you and involve them in the process.
- Ask for help. Talk with your doctor, nurse and social work counselor.
- Seek information and ask questions. Be an active participant in your health care plan.
- Set realistic goals. Make a to-do list and check off tasks as you complete them.

Your social work counselor can help you review this material. For assistance, call the Department of Social Work at 713-792-6195.

The information in this book is general in nature and for education purposes only. This workbook should not be interpreted as legal advice. Consult an attorney if you are seeking legal advice.

# TAB 1- Advance Care Planning

# Advance Care Planning

Advance care planning is a process that helps you understand and share your values, goals and wishes as they relate to your health care. The goal of advance care planning is to make sure you receive medical care that is consistent with your wishes.

You can start planning at any time –before, during or after your treatment.

Advance care planning allows you to:

- Think about what is important to you.
- Share your values and goals with others.
- Get information about types of life-sustaining treatments that are available.
- Decide what types of treatment you would or would not want to receive.
- Choose who will make decisions about your medical care if you are unable to speak for yourself and help prepare that person to make decisions.
- Complete advance directives and other forms to record your decisions.
- Review this information from time to time, and make changes as needed.

Making plans for future health care decisions can give you peace of mind. It can reduce confusion or disagreement among loved ones. If your loved ones know your wishes, they will be able to honor them.

## Getting Started

What is most important to you? Knowing your values and goals can help you make decisions about your care.

Use the following questions as a guide to think about your beliefs and values. Consider how they relate to your health and your wishes about your care.

What should we know about you as a person to provide the best care possible for you?

_____

_____

What are your beliefs about medical treatment, quality of life and living longer?

_____

_____

What are your spiritual and religious beliefs? How do they affect your decision making?

_____

_____

Are there any medical treatments that go against your beliefs? If yes, what treatments?

_____

_____

## Quality of Life

Quality of life is a person's overall well-being. People have different views on what is a good quality of life. Factors that may affect a patient's quality of life include:

- Treatments and their side effects
- How well symptoms are controlled
- Time spent with loved ones at home or in the hospital
- Ability to engage in activities
- Social and spiritual factors

What does a good quality of life mean to you?

_____

_____

_____

## Your Values

If you face a serious illness, permanent disability or death, what is most important to you? Use the number scale (1 to 5) below to rate the items in order of importance to you.

You may give several items the same number rating. Your answers may change over time.

____ Ability to speak to my loved ones

____ Ability to live as long as possible no matter what

____ Ability to communicate in some way even if I cannot speak

____ Ability to read, write or sing

____ Ability to eat and taste

____ Ability to walk

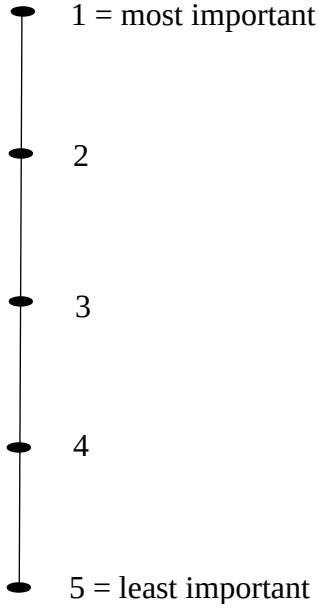
____ Being awake and thinking for myself

____ Being free from pain as much as possible

____ Maintaining as much control over my life as possible

____ Maintaining my dignity. (What does dignity mean to you?)

____ Other: _____



## Your Concerns

If you face a serious illness, permanent disability or death, what is most concerning to you? Use the number scale (1 to 5) below to rate the items in order of concern to you.

You may give several items the same number rating. Your answers may change over time.

____ Being in pain
____ Losing the ability to think
____ Losing the ability to communicate
____ Being a financial burden on loved ones
____ Being a physical burden on loved ones
____ Being an emotional burden on loved ones
____ Being removed from life support too soon
____ Being left on life support too long
____ Being unable to care for my loved ones
____ Leaving my loved ones behind
____ Leaving my pets behind
____ Other: _____

1 = most concerning

2

3

4

5 = least concerning

## Thinking About the End of Life

Use the following questions as a guide to think about your wishes related to the end of life.

As you get closer to the end of your life, what does having a good day mean to you?

_____

_____

What does a good death mean to you?

_____

_____

If it is possible, where would you like to be at the time of your death?

- ☐ Home
- ☐ Hospital
- ☐ Nursing home
- ☐ Hospice
- ☐ In bed
- ☐ Outdoors
- ☐ Other: _____

What kind of environment would you prefer?

- ☐ A well-lit room
- ☐ A warm place
- ☐ A quiet place
- ☐ Flowers nearby: _____
- ☐ Photographs nearby of: _____
- ☐ Music playing: _____
- ☐ Scent of : _____
- ☐ Other: _____

At the time of your death, who would you like to be with you? Or, would you like to be alone?

_____

_____

Thinking about the time (days or weeks) before your death, what would be important to you?

- ☐ Visit with family and friends
- ☐ Travel to: _____
- ☐ Make a list of things I want to do or see before I die
- ☐ Think about relationships and make amends where needed
- ☐ Work on a legacy activity such as creating a memory book
- ☐ Other: _____

## Life-Sustaining Treatments

If you are not able to speak for yourself, it is important that others know your preferences about medical care.

Life-sustaining treatments are types of medical care that may help you live longer. Five types of life-sustaining treatments to consider are:

- Breathing support
- Artificial hydration (fluids)
- Artificial nutrition
- Cardiopulmonary resuscitation (CPR)
- Dialysis

How each treatment might help you depends on your medical situation at the time. Learn and talk with your health care team about these treatments before you need them. This can make it easier to make important decisions later, if needed.

- Learn the facts about each treatment.
- Understand the benefits and risks and how they apply to you.
- Think about your preferences in different situations.
- Talk with your health care team and ask any questions.
- Talk with the people you trust and who care about you.

## Breathing Support

There may be times during your cancer treatment when it is hard to breathe and you might not be able to breathe on your own. There are invasive and non-invasive ways of receiving breathing support.

See *Breathing Support* in Appendix A to learn about the different types of breathing support:

- Simple nasal tubes and face masks
- High flow oxygen with nasal tubes
- Non-invasive ventilation with a face mask and Bi-PAP or C-PAP machines
- Intubation and mechanical ventilation
- Long-term intubation and mechanical ventilation (with tracheostomy)

What are your thoughts and preferences about the different types of breathing support?

_____

_____

_____

What questions do you have for your health care team about breathing support?

_____

_____

_____

## Artificial Nutrition and Hydration (Eating and Drinking Support)

There may be times during your cancer treatment when you are not able to swallow well or take in enough food and fluids to meet your body's needs. Food and fluids give your body energy. If you cannot eat or drink on your own, there are options for support.

Eating and drinking support is called artificial nutrition and hydration. Some forms of support are more invasive than others.

See *Tube Feeding (TF) and Total Parenteral Nutrition (TPN)* in Appendix A to learn about the different types of artificial nutrition:

- Nasogastric (NG) tube
- G- or J-tube
- Total parenteral nutrition (TPN) short-term
- Total parenteral nutrition (TPN) long-term

See *Hydration (Fluids)* in Appendix A to learn about the different types of artificial hydration:

- Nasogastric (NG) tube
- G- or J-tube
- IV tube
- Clysis

What are your thoughts and preferences about artificial nutrition and hydration?

_____

_____

_____

What questions do you have for your health care team about artificial nutrition and hydration?

_____

_____

_____

## Cardiopulmonary Resuscitation (CPR)

When a patient's heart or lungs stop working, the health care team performs CPR to try to bring the person back to life. CPR means the health care team will:

- Push on the chest bone to pump on the heart in an effort to restart the heart.
- Apply a breathing bag and mask to force air into the lungs.

The success of CPR can depend on the person's overall health before the heart or lungs stop working. Advanced cancer and other health conditions can affect the success of CPR.

Sometimes even when CPR is successful at restarting the heart or lungs, the patient's condition can get worse. For example, the patient could:

- Have permanent injuries, such as brain damage, due to lack of blood flow and oxygen to the brain.
- Have damage to other organs, such as the kidneys.
- Need to be on a ventilator for the rest of their life.
- Be in a coma.

What are your thoughts and preferences about CPR?

_____

_____

_____

What questions do you have for your health care team about CPR?

_____

_____

_____

## Dialysis

When a patient's kidneys do not work, dialysis treatment may be used to do some of the work of healthy kidneys. Dialysis cleans out harmful wastes, chemicals and fluid from the blood. It filters the blood and helps to keep a normal balance of fluids in the body. Dialysis does not treat the kidney condition. It performs some kidney functions for the person.

Dialysis treatment may be used for 2 types of kidney failure:

- Acute renal (kidney) injury/failure
- End stage kidney failure

There are different methods of dialysis. Talk with your doctor about which method would be appropriate for you.

For patients with acute kidney failure, dialysis treatment may be temporary. The kidneys may heal and go back to normal or almost normal.

For patients with severe end stage kidney failure, dialysis is a long-term treatment. The kidneys do not heal and cannot return to normal. The patient needs dialysis unless they can get a kidney transplant. Stopping dialysis may mean a patient will die sooner. Your goals, values and beliefs are important to consider. Talk with your doctor about the risks and benefits of dialysis for your situation.

The benefits and risks of dialysis treatment can depend on the person's overall health.

What are your thoughts and preferences about dialysis?

_____

_____

_____

What questions do you have for your health care team about dialysis?

_____

_____

_____

# Questions to Ask Your Doctor

There are many medical situations for you to consider. These may include side effects or disabilities from treatment, or changing the goal of your treatment from curing your cancer to managing symptoms. Your health care team can help you understand possible medical situations.

Read the following questions and note the ones you may want to discuss with your doctor. Add your own questions to the list.

## Questions About Treatment

- What is the goal of my treatment? Is it to cure, control or improve my symptoms?
- Will you openly discuss treatment options and outcomes with me?
- Why do you recommend this treatment?
- How long do you expect the treatment to last?
- What are my alternatives if I stop treatment or choose not to pursue further treatment?

## Questions About Side Effects

- Can I expect any permanent side effects from my treatment?
- If I continue treatment, how will it affect my quality of life?
- If I stop treatment or choose not to have treatment, how will it affect my quality of life?
- Will treatment affect my ability to become pregnant in the future?
- Will treatment affect my sex life?
- If I am in pain or have other symptoms, what help is available?

## Questions About Support

- Will you help me and my family make decisions?
- Will you help me get other support I may need (social work, chaplain, supportive care)?
- Will you tell me if treatment is no longer working?
- What is hospice care?
- Will you support my decision to transition to hospice if I am nearing the end of my cancer treatment?

## Other Questions

Are there other questions you want to ask your doctor?

_____

## Talking With Others

Conversations about advance care planning may not be easy, but they are important. Reasons to talk about these issues with others include:

- It may help you think about your wishes. Others may ask you questions or say things that make you think about your wishes in another way.
- Even if your wishes are in writing, loved ones are more likely to fully understand your wishes if you talk about them together.
- It can help your loved ones make difficult decisions in the future with less pain, stress or doubt.

As you talk about these issues, remember:

- You do not have to cover every topic in one conversation. Start a conversation and take small steps as needed.
- It is important to talk openly and honestly.

### Tips for Starting a Conversation

It can be difficult to start a conversation. Here are some tips to consider:

- Start by sharing your thoughts with others in writing or in a recording. Let them read or listen when they are alone. This may help them hear and process what you share. This also allows them to think and prepare for a conversation.
- Share this workbook with them.
- Share a story from a book, movie or the news about the topic.
  - Example: *"I knew the man was going to die at the end of the movie, but they never mentioned what happened to his family."*
- Share a story about someone you know.
  - Example: *"Do you remember what happened to so-and-so? Her family went through so much. I don't want you to have to go through that with me."*
- Blame it on someone else.
  - Example: *"My health care team at MD Anderson asked me several times about advance care planning. They said I should talk to you about it."*

Some people may try to avoid the conversation. Here are some tips for how to respond:

- Be direct and straightforward. It's OK to acknowledge that it is difficult or uncomfortable.
  - Example: *"I know this is difficult for you, but I need you to listen to me. It's very important to me"*
- Point out what could happen if you don't talk
  - Example: *"If we don't do this, we could end up in a worse situation. I'd like to avoid that."*

# Tab 2 – Record Medical Wishes

# Documents to Record Your Medical Wishes

There are special documents to record your wishes about treatment and who you would like to make decisions for you if you cannot speak for yourself.

Some of the documents are a certain type of legal document called an **advance directive**. The other forms may be part of your advance directives and also help to record your wishes.

The 2 charts below outline key points about each document. Documents require signatures from different people. Some may require witnesses or a notary. A **notary** is person who has the legal power to verify that documents are true and correctly signed.

## Advance Directives

| Name of document | What it records | When it is used | Signed by a doctor? | Witnesses needed |
|---|---|---|---|---|
| **Medical Power of Attorney** (Also called Durable Power of Attorney for Health Care) | **Who will speak for you** in regard to decisions about your medical care | If you are unable to speak for yourself to make decisions about your medical care | No | 2 witnesses **or** notary |
| **Living Will** (Also called Directive to Physicians and Family or Surrogates) | **What you want** in regard to specific decisions about your medical care | If you are unable to speak for yourself to make decisions about your medical care | No | 2 witnesses **or** notary |
| **Out-of-Hospital Do-Not-Resuscitate (DNR) Order** | You **do not** wish to have CPR | If your heart or heart and lungs stop working when you are **outside of the hospital** (at home, in the community) | **Yes**<br><br>(This is a medical order and advance directive.) | None |

## Other Documents

| Name of document | What it records | When it is used | Signed by a doctor? | Witnesses needed |
|---|---|---|---|---|
| **Appointment of Disposition of Remains** | **Who will make decisions** about you after your death | After your death | No | 2 witnesses **and** notary |
| **In-Hospital Do-Not-Resuscitate (DNR) Order** | You do not wish to have CPR | If your heart or heart and lungs stop working **when you are in the hospital** | **Yes**<br><br>(This is a medical order.) | None |

Medical Power of Attorney, Living Will, Appointment of Disposition of Remains and Out-of-Hospital Do-Not-Resuscitate Order blank forms are available in the back of this workbook, in **Appendix B**.

**Consider the following tips as you work through your documents:**

- When you have chosen a medical power of attorney, make sure to include them in conversations about your wishes.
- Give copies of your documents to your medical power of attorney and all medical providers.
- You may update your documents as often as you wish. Make sure you review them from time to time.

## Medical Power of Attorney

This advance directive names someone to make decisions for you if you are unable to speak for yourself, whether permanent or temporary. In the event that you cannot make decisions for yourself, this person will make decisions for you.

The person you choose is also called your medical power of attorney.

Choosing a medical power of attorney may not be an easy choice, but it is important. It is especially important for individuals who are separated, not legally married or have more than one adult child.

Choose someone who will honor, respect and follow your wishes. Your medical power of attorney should be someone who:

- Is willing to speak on your behalf.
- Is willing to act according to your wishes.
- Can be there for you when you need them.
- Understands what is important to you.
- Is willing to ask important questions and understand the possible outcomes of medical decisions.
- Is willing to talk with you about sensitive or difficult issues.
- Can handle conflicting opinions among family, friends and medical providers.

The responsibility of being a medical power of attorney can be emotionally difficult. Share your values and goals with the person you choose. They will have the power to follow your wishes and make decisions when you cannot.

### Legal Next of Kin

If you do not choose a medical power of attorney, most U.S. states will designate someone based on a list of people who qualify as your next of kin. Each state has different laws about medical power of attorney.

When you are in Texas receiving care, Texas laws apply to you. Your social worker can help you find information about legal next of kin in other states, if needed.

In the State of Texas, the following people can qualify as your next of kin, in order of priority:

1. Your spouse (even if you are separated)
2. Your adult child (if your other adult children agree to this person being the decision-maker)
3. A majority of your reasonably available adult children
4. Your parents
5. A person you have clearly identified to make decisions for you, your nearest living relative or a member of the clergy

**This legal next of kin order may not be in line with your wishes, so it is important to complete your Medical Power of Attorney document.**

### Medical Power of Attorney Flexibility

You may consider how much flexibility you want to give your medical power of attorney. Flexibility means allowing your medical power of attorney to make decisions that are different from what you have expressed, based on what is most beneficial for you at the time.

Consider the following levels of flexibility:

- **Total flexibility** means your medical power of attorney could change your previously stated wishes if he or she thinks it is better for you (and your doctor thinks it is medically appropriate).
- **Some flexibility** means there are some wishes your medical power of attorney cannot change. You should record these specific wishes.
- **No flexibility** means your medical power of attorney should not change any of your wishes. They should honor your wishes with no exceptions, if it is considered medically appropriate.

To choose your medical power of attorney's level of flexibility, see the *Additional Requests* section on the Medical Living Will form (on page 2).

## **(Medical) Living Will** (Directive to Physicians and Family or Surrogates)

This advance directive is an outline of your health care wishes. It gives specific details about what treatment you do or do not want. A Living Will takes effect only when you are in the terminal or irreversible phase of illness or injury. It addresses the use of comfort care and life-sustaining treatments (such as artificial nutrition, hydration, dialysis, and breathing support).

Parents may complete a Medical Living Will for a child under age 18.

If you sign a Medical Living Will, talk with your doctor about the directive and ask to have a copy added to your medical record.

## Appointment for Disposition of Remains

This document allows you to choose a person to make decisions about you after your death. This person makes decisions about your body, funeral and other final arrangements.

Your medical power of attorney's responsibility ends at the time of your death. In Texas, if you do not have an Appointment for Disposition of Remains, your legal next of kin controls the decisions after your death.

### Legal Next of Kin

In Texas, if you do not have an Appointment for Disposition of Remains, the following people can qualify as your next of kin, in order of priority:

1. Your spouse (even if you are separated)
2. Any one of your adult children
3. Either of your parents
4. Any one of your adult siblings
5. Any one of your executors of your estate
6. Any one of your adult next of kin, in the order named by law to inherit your estate

**If this legal next of kin does not agree with your wishes, be sure to complete this form.**

# Do-Not-Resuscitate (DNR) Orders

Do-not-resuscitate (DNR) orders tell the health care team not to perform CPR.

A DNR order only addresses the use of CPR. If a health care provider feels that chemotherapy or another form of medical care may help, the patient may receive that treatment. You will always receive care focused on keeping you comfortable.

There are 2 types of DNR orders: In-Hospital DNR and Out-of-Hospital DNR.

## In-Hospital Do-Not-Resuscitate (DNR) Order

The doctor writes this order when the patient is admitted to the hospital. It lasts until a doctor cancels the order or the patient is discharged from the hospital. A new In-Hospital DNR must be written each time the patient is admitted to the hospital.

## Out-of-Hospital Do-Not-Resuscitate (DNR) Order

An Out-of-Hospital Do-Not-Resuscitate (DNR) order is a medical order that tells a health care team not to perform CPR if your heart or lungs stop working when you are outside the hospital. This is an order signed by a doctor.

If you do not have an Out-of-Hospital DNR order and your heart or lungs stop working properly, health care providers may do everything medically possible to restart your heart and help you breathe.

**To show you have an Out-of-Hospital DNR order, you must have a copy of the DNR order, DNR bracelet or DNR necklace with you at all times.**

**Be sure to give a copy of this document to your medical care team.**

Each state has different DNR forms and laws. If your home is in another state, you may want to ask your primary care provider about DNR orders in your home state. Your social work counselor can also help you find answers about DNR orders outside of Texas.

Talk with your doctor or social work counselor to obtain an Out-of-Hospital DNR order.

# TAB 3 – Financial Planning

# Financial Planning

In addition to medical advance directives, planning for help with your finances is important. For financial planning, you may want to consider completing these legal documents:

- Durable Power of Attorney
- Last Will and Testament

You can find these legal documents online and in many office supply stores. Signatures on these documents may require a **notary**. A notary is person who has the legal power to verify that documents are true and correctly signed.

## Durable Power of Attorney

This document allows you to choose a person to handle your money matters if you are unable to make decisions for yourself. Laws about Durable Power of Attorney are different for each state. You may want to work with an attorney to complete this document.

## Last Will and Testament

This document states your final wishes about your personal belongings and your dependents. It allows you to record your wishes about what happens after your death, including:

- Who receives your assets
- Who becomes the executor for your estate. The executor:
  - Carries out the details of your Last Will and Testament.
  - Manages your financial matters (Durable Power of Attorney ends at the time of your death).
  - Is the only person who is able to access your medical records after your death.

## Planning for Guardianship

If you have children under the age of 18, consult an attorney about guardianship, custody, trusts and any special circumstances. You may also use your Last Will and Testament to name a guardian for your children.

## Planning Tools

The next pages provide space for you to write down important information about your financial information, documents, contacts and online accounts. This tool can help you stay organized and help your loved ones find information if they need it.

## Financial Information

| Financial Assets and Loans | Institution Name | Account Number | Username and Password |
|---|---|---|---|
| Checking Account | | | |
| Savings Account | | | |
| Other Account | | | |
| Credit Union Account | | | |
| Investments (Stocks or Bonds) | | | |
| Mutual Fund Accounts | | | |
| Retirement Accounts (401k, 403b, IRA) | | | |
| Pensions | | | |
| Mortgages | | | |
| Credit Cards | | | |
| Personal Loans | | | |
| Student Loans | | | |
| Health Insurance/ Health Savings Account | | | |
| Homeowner’s Insurance/ Flood Insurance | | | |
| Car Insurance | | | |
| Life Insurance | | | |
| Long-term Care Insurance | | | |
| Social Security Card/ Statement | | | |
| Phone Bill | | | |
| Gas Bill | | | |
| Electric Bill | | | |
| Water Bill | | | |

## Documents and Items

| Important Documents | Location | Other Information |
|---|---|---|
| Property Paperwork (House Deed, Car Title) | | |
| Safe Deposit Box | Institution:<br>Box#:<br>Key location: | |
| Military Paperwork | | |
| Durable Power of Attorney | | |
| Medical Power of Attorney | | |
| Living Will | | |
| Last Will and Testament/ Trusts | | |
| Beneficiary Designations for Retirement Accounts | | |
| Marriage License | | |
| Divorce Decree | | |
| Cemetery Plot Information | | |
| Pre-arranged Funeral Plans | | |
| Past Tax Returns | | |
| Picture ID and Birth Certificate | | |
| | | |
| | | |
| | | |

## Key Contacts

| Key Contacts | Contact Name and Company | Contact Information |
|---|---|---|
| Employer | | |
| Accountant/ Financial Advisor | | |
| Physicians | | |
| Lawyer | | |
| Spiritual/Religious Community | | |
| Family/Friends | | |
| | | |
| | | |

## Social Media and Other Online Account Information

| Websites and Devices | Username | Password |
|---|---|---|
| Computer | | |
| Mobile Phone | | |
| MyChart | | |
| Facebook | | |
| Twitter | | |
| Instagram | | |
| | | |
| | | |

# TAB 4 – Legacy Making

# Legacy Making

## Understanding Legacy Work

Legacy work is the act of putting your thoughts, advice, values and wishes into actual items that your loved ones can cherish year after year. It is not about death and dying. It is about life and living.

Your cancer diagnosis is only one part of your life. People know you by other characteristics, values and stories. Legacy work allows you to help create memories in meaningful ways for you and your loved ones. It is about making connections and sharing precious moments with the special people in your life.

The next pages in this workbook are to help you think about your own legacy work. Use the space to write your thoughts and ideas. Chaplains and social work counselors can help you think about and plan your legacy work.

## Legacy Topics

Many people do not know where to start with planning legacy activities. The following list of topics may help you think about ideas:

- Favorites
- Family history
- Childhood
- Adulthood
- Accomplishments and achievements
- Gratitude
- Overcoming challenges
- Traditions
- Relationships
- Milestones
- Lessons learned
- Hopes and dreams
- Spirituality
- Religion

## Legacy Activities

Legacy making can take many forms. There is no wrong way to do legacy work. Use the list of example activities below to think about what works for you.

**Written**
- Letters
- Stories
- Journals
- Gratitude list
- Poems
- Blogs

**Audio and Visual**
- Playlists
- Professional videos
- Homemade recordings
- Digital photo frame
- Slideshow

**Crafts**
- Scrapbook
- Collage
- Photobook
- Family tree
- Quilt or blanket
- Artwork
- Hand or footprint
- Lock of hair

**Other**
- Recipe book
- Heirlooms and keepsakes
- Traditions and routines
- Meaningful gift
- Financial gift
- Organization or scholarship fund

## Tips for Legacy Activities

Legacy making is not just an end of life activity. It is a way to engage with the people you care about at any stage of your cancer treatment. Physical challenges, difficult emotions and time constraints may influence your ability to do some types of legacy work. But there are often ways you can work around the challenges. The following tips may help you prepare for legacy activities and help you address the challenges you face.

**Appearance**
***Tip:*** Consider projects that use writing, crafts, audio recordings or photos from the past.

**Cultural and Spiritual Values**
***Tip:*** Reflect on your personal values and beliefs. Decide what you are comfortable doing. Talk with a loved one or spiritual advisor about your thoughts and feelings.

**Decreased Energy**
***Tip:*** Legacy activities do not have to be completed all at one time. Do as much as you feel able to do. You can work on small parts of projects over time, and ask others to help.

**Emotions**
***Tip:*** Work on legacy projects in the way that is best for you. This may include doing one project all at one time, in small parts over time, asking others to help you, or doing a group activity.

**Voice**
***Tip:***. Consider using audio recording of your voice from the past, or create a video by holding up posters with written messages. Projects without audio can also be successful at delivering your message.

**Inability to Write**
***Tip:*** Choose projects that involve photo, audio or visual recordings. You can also dictate your stories and letters. The words are still yours and come from your heart.

**Mental State**
***Tip:*** Ask your medical team if there is a way to temporarily adjust your medicines or treatment to increase clarity and awareness. If adjustments are not possible, consider activities (such as writing letters) that can be done in small parts. You can start and stop the activity as needed.

**Time**
***Tip****:* Schedule time on your calendar for legacy making activities. Set aside the time you need to work on projects. Set realistic goals.

# TAB 5 – Spirituality/End of Life

# Spirituality and End of Life Planning

## Rituals

Spirituality refers to the way people seek and express meaning and purpose in their life. It includes how people experience connectedness to others, nature, themselves, and anything they consider significant or sacred. Spirituality can include religion, but is not limited to religious practices. People express and experience spirituality in different ways.

It is important that the people who care about you know how your spirituality relates to your preferences about end of life customs, rituals or other activities you wish to have. Talk about this early so that your loved ones can honor your wishes.

What customs or rituals are important to you?

_____

_____

At the end of your life, what do you want to happen? What do you not want to happen?

_____

_____

Do you have a spiritual community, advisor or representative?

_____

## Celebrations of Life and Funeral Planning

For most people, planning services for after death is an unfamiliar process. You may want to consider pre-arranging plans. Your planning can help to ease the burden on your loved ones when they have to carry out your final wishes. It can decrease their financial and emotional stress in the future.

Funeral homes can guide you through your options and keep your wishes on file. Celebrations of life may be held at different locations. Think about what is important to you. What kind of service do you want? Where should it be? Are there certain rituals you would like to happen?

You may consider personalizing the service to honor your spiritual beliefs or faith tradition, military service, fraternity/sorority or other special requests.

**Contact information for funeral home or service location:**

_____

_____

**I wish to be:**

- ☐ Buried (Location_____)
  - Buried next to: _____
  - Tombstone engraving: _____
- ☐ Cremated
  - What do you want to happen to your ashes?

    _____
  - If you want your ashes to be scattered, where?

    _____
- ☐ Other:_____
- ☐ Whole Body Donation – Allows you to donate your body for medical research and education. Most medical institutions have acceptance criteria. Check with your local medical school.
- ☐ Organ and Tissue Donation – Allows you to donate certain organs and/or tissue. This is also subject to the acceptance criteria of medical institutions. In Texas, for example, you may visit **www.donatelifetexas.org** for more information or to register online.

You can personalize your service or celebration. What details would you like? You may think about flowers, music, clothing, speakers, pallbearers, readings, food, slideshow, and anything else important to you.

_____

_____

## Obituary Writing

You may choose to write your own obituary. As you write, consider what is important to you to mention. Some examples include:

- Proud or meaningful moments
- Accomplishments
- Favorite memories
- Hobbies and activities
- Family jokes or traditions

# TAB 6 – Coping and Support

# Coping and Support

Advance care planning involves thinking about challenging topics. Making informed decisions may take time, and you may not know all the answers. Remember that going through this process now can help give you and your loved ones peace of mind in the future.

It may not be easy to think and talk about the topics in this book.

- Take your time.
- Think about your choices.
- Talk with your loved ones.
- Talk with your medical team.
- Ask any questions you may have.

## How Social Work Counselors Can Help

Social work counselors can assist with advance care planning, including help with:

- Working through your emotions and feelings
- Preparing for conversations with your loved ones
- Explaining concepts in this workbook
- Completing some legal documents
- Legacy making
- Finding additional resources

In addition to help with advance care planning, social work counseling is available to you and your loved ones at no cost. Counseling services include:

- Adjustment to diagnosis and treatment
- Coping with life changes
- Crisis intervention
- Grief and loss
- Sexuality counseling
- Family counseling
- Specialized care programs:
  - CLIMB: Children's Lives Include Moments of Bravery
  - KIWI: Kids Inquire, We Inform
- Bereavement and loss counseling
- Relaxation therapies

To contact your social work counselor, call 713-792-6195.

## How Chaplains Can Help

Chaplains are available to assist in the following ways:

- Help you clarify your values and beliefs
- Help you understand your options
- Help with difficult conversations about your end of life wishes
- Help you with spiritual or religious questions or concerns
- Help you plan and prepare final arrangements. Chaplains can also provide end of life rituals, prayers and sacraments.
- Help connect you with representatives from your spiritual community or faith group

To contact a chaplain, call 713-792-7184.

## How the Supportive Care Team Can Help

Supportive Care team members are available to assist in the following ways:

- Help you manage your symptoms
- Help you think about your wishes for advance care planning
- Help you work through your emotions and feelings
- Help you connect with additional community support

To contact the Supportive Care team, call 713-792-6072.

## Support for Caregivers

Advance care planning involves serious topics and careful thinking. The process can be emotional for patients and caregivers. It is normal to have good and bad days. As a caregiver, your role in advance care planning is to gain knowledge and support your loved one. It is also important that you have support during this process.

### How You Can Support Your Loved One

- You can listen and talk with your loved one. Ask questions and challenge your loved one's ideas in a gentle way to make sure they are certain about their decisions.
- Help your loved one maintain control of their care. Support their wishes and advocate on their behalf.

### Tips for Supporting Yourself as a Caregiver

- Take time for yourself and practice self-care.
- Set reasonable boundaries with your loved one.
- Know your own thoughts about advance care planning. You may need to process difficult feelings and accept the possibilities and outcomes.
- Find support in someone you trust. This may be a friend, a member of the clergy or your social work counselor.

## Talking With Children

Honest information is best for children. It is good to show them that talking about cancer and asking questions is OK. It will help them adjust to your illness, no matter what happens.

Sometimes children do not ask all of their questions. They might make up their own answers and imagine things that are worse than reality.

- If you have not already done so, tell your children about your cancer, and/or your prognosis, as age appropriate.
- Talk to your children about all of the people who will take care of them.
- Engage in legacy work with them (see Legacy Making section of this workbook).
- Engage your children in the advance care planning process as appropriate.

Ask for help with knowing the best way to talk with your children. Support is available from the Department of Social Work, Spiritual Care and Education Center, and Supportive Care Center.

## Additional Resources

A video series about advance care planning topics is available online. Use the links below to watch and learn more:

- **Advance Care Planning: Conversations Worth Having!**
  http://bit.ly/TalkACP
- **Part 1: What is Advance Care Planning?**
  http://bit.ly/MDAACP1
- **Part 2: Quality of Life**
  http://bit.ly/MDAACP2
- **Part 3: Involving Loved Ones**
  http://bit.ly/MDAACP3
- **Part 4: Choosing a Patient Representative**
  http://bit.ly/MDAACP4
- **Part 5: Advance Directives**
  http://bit.ly/MDAACP5
- **Legacy: Making Memories Last**
  http://bit.ly/MDALegacy

Read more about advance care planning online at www.mdanderson.org/advancecareplanning.

# TAB 7 - Appendix A

# Appendix A

# Breathing Support

There may be times during your cancer treatment when it is hard to breathe or you may not be able to breathe on your own. If this happens, your health care team will work with you to decide the best treatment plan for you.

We encourage you to learn and talk with your care team about breathing treatments before you need it.

- Learn the facts about each treatment.
- Understand the benefits and risks and how they apply to you.
- Talk with your health care team and ask any questions.
- Talk with the people who you trust and care about you.

## Causes

There can be many reasons for breathing problems. Some of the more common reasons for patients with cancer are:

- Not getting enough oxygen (low blood oxygen levels). This may happen for many reasons.
- Cancer of the lung or cancer that has spread to the lungs.
- Fluid around the heart or lungs.
- Lung infections or pneumonia.
- Heart failure (when the heart is weak and cannot pump normally).
- Inflammation of the lungs due to treatment or medicines.
- Blood clots in the lung.
- Asthma or chronic obstructive pulmonary disease (COPD).
- Generalized weakness which can involve the breathing muscles.
- Anything that causes the abdomen to push up on the diaphragm, such as fluid or a tumor. When this happens, the lungs have less room to expand when breathing.

## Treatment

Depending on the reason for your breathing problem and your goals of care, your doctor will work with you to choose the best treatment(s). Treatments may include:

- Antibiotics for pneumonia
- Medicines or procedures to help remove extra fluid
- Steroids for inflammation
- Breathing treatments for asthma or COPD
- Exercise and therapy for weak muscles
- Anticoagulants for blood clots
- Chemotherapy, radiation treatment, or surgery for a tumor
- Oxygen for low blood oxygen levels

## Breathing Support

Breathing support is a way to give your body more oxygen. You may need breathing support if you are not able to take in enough oxygen by breathing on your own. There are several types of breathing support. The best type for you depends on how much oxygen you need. Your doctor will help you decide which type is best for you.

These simple types of breathing support can be given at home or in the hospital:

- Nasal tubes (tubes placed in your nose) that deliver oxygen
- A face mask that covers your nose and mouth that delivers oxygen

If you need higher amounts of oxygen, you may need another type of oxygen support. These types are described below.

### High-Flow Oxygen

This type of oxygen support involves using a special nasal tube. If simple nasal tubes do not meet your oxygen needs, high-flow oxygen may be an option. You cannot receive this type of oxygen at home. **You will need to stay in the hospital as long as you need this treatment.**

### Non-Invasive Ventilation With Bi-PAP or C-PAP

This type of oxygen support is delivered by a mechanical ventilator (breathing machine). Oxygen is pushed through a tightly-fitted face mask. This type of oxygen support uses pressure to push oxygen into the lungs. You may need to wear the face mask at all times. This can make it hard to eat and talk.

### Intubation and Mechanical Ventilation

Most often, this type of oxygen support is for patients who have respiratory failure and cannot breathe on their own. Intubation means placing a tube into the airway (or trachea) through the nose or mouth. A ventilator or breathing machine pushes oxygen through the intubation tube into the lungs.

Patients who receive this type of oxygen are usually in the intensive care unit. If patients need this type of oxygen support for a long time, a more permanent kind of tube (tracheostomy tube) is surgically placed in the airway.

Intubated patients on a ventilator are not able to speak and will need to communicate in other ways, such as by writing or using sign language. Your doctor may give you medicine to make you less anxious. The medicine may make you sleepy and make it hard to communicate with others. Risks of intubation and mechanical ventilation include:

- Infection
- Lung damage
- A collapsed lung

A breathing machine does not treat disease, but helps you breathe while your health care team tries to improve your physical condition. The goal is to have you breathe on your own as soon as possible. If your lungs do not get strong enough, you may need oxygen support from the

ventilator permanently. At this stage, you and your health care team may decide to stop the ventilator and focus on making you comfortable.

## Your Treatment Decisions

When you think of breathing treatments, it is important to know the purpose of each type of treatment. Ask these questions:

- Will it fix the cause of the problem?
- What are the side effects and risks of each treatment?

Your treatment plan may depend on the answers to these questions. Your values and goals may also affect your decision. Some patients may choose to try a treatment, and some patients decide breathing treatments are not right for them. Comfort care may be the main goal at this time.

Talk with your doctor or nurse about any questions or concerns you have.

# Artificial Nutrition

There may be times during your cancer treatment when you are unable to swallow well or take in enough food and liquid to meet your body's needs. Artificial nutrition may help you get the nutrition you need. If this happens, your health care team will work with you to decide the best treatment plan for you.

The following information explains the different ways patients can receive artificial nutrition. We encourage you to learn and talk with your care team about this treatment before you need it.

- Learn the facts about each treatment.
- Understand the benefits and risks and how they apply to you.
- Talk with your health care team and ask questions.
- Talk with the people who you trust and care about you.

## Types of Artificial Nutrition

Artificial nutrition is a way to get nutrition and hydration without taking in food and drink through the mouth. Artificial nutrition feeds the body through tubes, which may be placed:

- Through the nose into the stomach
- Through a cut in the skin and then into the stomach or small intestine
- Into a vein (intravenous or IV)

### Tube Feeding (TF)

Tube feeding is a way to get artificial nutrition through a tube that is placed into your stomach or intestine. Depending on your medical needs, this tube goes through the nose or through the skin in your abdomen.

A tube placed through the nose into the stomach is called a nasogastric (NG) tube. This is usually a short-term way to place a feeding tube.

If the feeding tube needs to be in place for a longer time, a tube may be placed through the skin into the stomach (G-tube) or small intestine (J-tube). For some patients, this procedure may require surgery.

### Total Parenteral Nutrition (TPN)

Feeding by IV is known as total parenteral nutrition (TPN). For TPN, the IV tube is connected to a bag of liquid formula which goes from the bag, through the tube, into a vein. This method works best when the body cannot absorb feedings through the stomach or intestines.

For TPN, patients receive a central venous catheter (CVC). A CVC is a tube that is usually placed into a large vein in the arm or under the collarbone. A CVC is a long-term way to place a tube, but can be removed when you no longer need it.

## Benefits of Artificial Nutrition

Additional feedings may be helpful when you:

- Are preparing for surgery
- Cannot eat after surgery
- Have wounds that need to heal
- Have a blocked bowel (bowel obstruction)
- Cannot swallow because of a blocked esophagus or from oral surgery
- Cannot swallow because of severe pain in the mouth or esophagus caused by radiation, chemotherapy, infection or for other reasons

## Your Treatment Decisions

Artificial nutrition may not be right for all patients. The benefits and risks of each treatment may depend on your health status and goals. Sometimes, a patient's body cannot use the nutrition properly and does not tolerate artificial nutrition. This often happens in the later stages of illness, when the body begins to shut down. Comfort care may be the primary goal of care at this time.

At this stage, most people are not hungry. Good oral hygiene can help the patient stay comfortable, and just a few sips of fluid or a few bites of food is enough.

Talk with your doctor, nurse and dietitian about any questions or concerns you have.

# Artificial Hydration (Fluids)

There may be times during your cancer treatment when you are not able to swallow well or take in enough liquids to meet your body's needs. Artificial hydration may help you get the fluids you need. If this happens, your health care team will work with you to decide the best treatment plan for you.

The following information explains the different ways patients can receive fluids. We encourage you to learn and talk with your care team about artificial hydration before you need it.

- Learn the facts.
- Understand the benefits and risks and how they apply to you.
- Talk with your health care team and ask questions.
- Talk with the people who you trust and care about you.

## Types of Artificial Hydration

Artificial hydration is a way to give the body fluids through a tube. The fluids are absorbed into the blood stream. Artificial hydration can enter the body through a tube in several ways:

- Into the stomach or intestine
- Into a vein (intravenous or IV)
- Under the skin into fatty tissue

With any of these methods, patients may receive fluids as needed or on a continuous basis (24 hours a day).

### Stomach (NG Tube or G-Tube) or Intestinal Tube (J-Tube)

When a tube is needed only for a short time, it is usually placed through the nose into the stomach. This is called a nasogastric (NG) tube.

If the tube needs to be in place for a longer time, a tube may be placed through the skin into the stomach (G-tube) or small intestine (J-tube). This procedure may not require surgery.

### IV Tube

When fluids are given by IV, the IV tube is connected to a bag of fluids which goes from the bag, through the tube, into a vein.

If patients need fluids long-term, they usually receive a central venous catheter (CVC). A CVC is a tube that is usually placed into a vein in the arm or under the collarbone. A CVC is a long-term method of artificial hydration, but it is removed when the patient no longer needs it.

### Tube Under the Skin Into the Fatty Tissue (Clysis)

Patients may receive fluids through a tube placed under the skin into the fatty tissue. This is called hypodermoclysis, or clysis, for short. The fluid is absorbed from the fatty tissue into the bloodstream.

Clysis does not give the body as much fluid as artificial hydration with an IV tube. This method works best for patients who need a modest amount of fluids. It is simpler, with fewer complications. Some hospice services provide clysis, but all health care providers may not provide this treatment.

## Benefits of Artificial Hydration

Patients receive fluids through a tube to prevent or treat dehydration. Patients who are dehydrated may feel weak, dizzy or thirsty. These symptoms may also happen for other reasons. Depending on the cause, fluids may help the symptoms. If artificial hydration does not help, other treatments are available to help these symptoms.

## Possible Complications

Some complications that may happen with artificial hydration are below. Patients receive treatment for complications as needed.

### Stomach (NG Tube or G-Tube) or Intestinal Tube (J-Tube)

Complications may include:

- Nose and throat soreness (for tubes placed through the nose)
- Skin soreness
- Infection
- Tube misplacement
- The tube falls out
- The tube gets clogged
- The tube leaks

### IV Tube

Complications may include:

- Soreness at the IV site
- Infection at the IV site
- Infections of the bloodstream
- Blood clots at the IV site
- Too much fluid, which may cause swelling or breathing problems

### Tube under the Skin into Fatty Tissue (Clysis)

Complications may include:

- Uncomfortable swelling at the tube site
- Infection at the tube site

## Your Treatment Decisions

Artificial hydration may not be right for all patients. Sometimes the treatment has more risks than benefits. For some patients, the body cannot use the fluids properly. This often happens in the later stages of an illness, when the body begins to shut down. Comfort care may be the main goal of care at this time.

Caregivers often worry that their loved ones will be thirsty without water. Most people in this situation do not feel thirsty. If they are thirsty, very small amounts of fluids and good mouth care will keep the mouth clean and feeling refreshed.

Talk with your doctor or nurse about any questions or concerns you have.

# TAB - Appendix B

THE UNIVERSITY OF TEXAS
MD Anderson Cancer Center
Making Cancer History®

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

# Medical Power of Attorney

Disclosure Statement

**THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE SIGNING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:**

Except to the extent you state otherwise, this document gives the person you name as your agent the authority to make ANY and ALL health care decisions for you in accordance with your wishes, including your religious and moral beliefs, when you are no longer capable of making them yourself. Because "health care" means any treatment, service or procedure to maintain, diagnose, or treat your physical or mental condition, your agent has the power to make a broad range of health care decisions for you. Your agent may consent, refuse to consent, or withdraw consent to medical treatment and may make decisions about withdrawing or withholding life-sustaining treatment. Your agent may not consent to voluntary inpatient mental health services, convulsive treatment, psychosurgery, or abortion. A physician must comply with your agent's instructions or allow you to be transferred to another physician.

Your agent's authority begins when your doctor certifies that you lack the competence to make health care decisions. Your agent is obligated to follow your instructions when making decisions on your behalf. Unless you state otherwise, your agent has the same authority to make decisions about your health care as you would have had.

It is important that you discuss this document with your physician or other health care provider before you sign it to make sure that you understand the nature and range of decisions that may be made on your behalf. If you do not have a physician, you should talk with someone else who is knowledgeable about these issues and can answer your questions. You do not need a lawyer's assistance to complete this document; but, if there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

The person you appoint as agent should be someone you know and trust. The person must be 18 years of age or older or a person under 18 years of age who has had the disabilities of minority removed. If you appoint your health or residential care provider (e.g., your physician or an employee of a home health agency, hospital, nursing home, or residential care home, other than a relative), that person has to choose between acting as your agent or as your health or residential care provider; the law does not permit a person to do both at the same time.

You should inform the person you appoint that you want the person to be your health care agent. You should discuss this document with your agent and your physician and give each a signed copy. You should indicate on the document itself the people and institutions who have signed copies. Your agent is not liable for health care decisions made in good faith on your behalf.

Even after you have signed this document, you have the right to make health care decisions for yourself as long as you are able to do so and treatment cannot be given to you or stopped over your objection. You have the right to revoke the authority granted to your agent by informing your agent or your health or residential care provider orally or in writing or by your execution of a subsequent *Medical Power of Attorney.* Unless you state otherwise, your appointment of a spouse dissolves on divorce.

This document may not be changed or modified. If you want to make changes in the document, you must make an entirely new one.

Initials: _____ Date/Time:_____

You may wish to designate an alternate agent in the event that your agent is unwilling, unable, or ineligible to act as your agent. Any alternate agent you designate has the same authority to make health care decisions for you.

**THIS POWER OF ATTORNEY IS NOT VALID UNLESS:**

**(1) YOU SIGN IT AND HAVE YOUR SIGNATURE ACKNOWLEDGED BEFORE A NOTARY PUBLIC; OR**

**(2) YOU SIGN IT IN THE PRESENCE OF TWO COMPETENT ADULT WITNESSES.**

**THE FOLLOWING PERSONS MAY NOT ACT AS ONE OF THE WITNESSES:**

(1) the person you have designated as your agent;
(2) a person related to you by blood or marriage;
(3) a person entitled to any part of your estate after your death under a will or codicil executed by you or by operation of law;
(4) your attending physician;
(5) an employee of your attending physician;
(6) an employee of a health care facility in which you are a patient if the employee is providing direct patient care to you or is an officer, director, partner, or business office employee of the health care facility or of any parent organization of the health care facility; OR
(7) a person who, at the same time this *Power of Attorney* is executed, has a claim against any part of your estate after your death.

*I have received, read and understood this Medical Power of Attorney Disclosure Statement.*

Signature: _____Date/Time: _____

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MD Anderson Cancer Center
Making Cancer History®

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

# Medical Power of Attorney

***DESIGNATION OF HEALTH CARE AGENT:***

I,_____(insert your name), appoint:

Name: _____

Address: _____

Phone: _____

as my agent to make any and all health care decisions for me, except to the extent I state otherwise in this document. This Medical Power of Attorney takes effect if I become unable to make my own health care decisions, and this fact is certified in writing by my physician.

LIMITATIONS ON THE DECISION-MAKING AUTHORITY OF MY AGENT ARE AS FOLLOWS:

_____

_____

_____

***DESIGNATION OF AN ALTERNATE AGENT:***
*(You are not required to designate an alternate agent, but you may do so. An alternate agent may make the same health care decisions as the designated agent if the designated agent is unable or unwilling to act as your agent. If the agent designated is your spouse, the designation is automatically revoked by law if your marriage is dissolved.)*

If the person designated as my agent is unable or unwilling to make health care decisions for me, I designate the following person(s) to serve as my agent to make health care decisions for me as authorized by this document, who serve in the following order:

A. First Alternate Agent
Name: _____

Address: _____

Phone: _____

B. Second Alternate Agent
Name: _____

Address: _____

Phone: _____

Initials: _____ Date/Time:_____

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

1. The original of this document is kept at:_____

_____

_____

2. The following individuals or institutions have signed copies:

Name: _____

Address: _____

Phone: _____

Name: _____

Address: _____

Phone: _____

**DURATION:** I understand that this *Power of Attorney* exists indefinitely from the date I execute this document unless I establish a shorter time or revoke the *Power of Attorney*. If I am unable to make health care decisions for myself when this Power of Attorney expires, the authority I have granted my agent continues to exist until the time I become able to make health care decisions for myself.

**(IF APPLICABLE)** This *Power of Attorney* ends on the following date: _____

**PRIOR DESIGNATIONS REVOKED:** I revoke any prior Medical *Power of Attorney.*

**ACKNOWLEDGMENT OF DISCLOSURE STATEMENT:** I have been provided with a disclosure statement explaining the effect of this document. I have read and understand the information contained in the disclosure statement.

Initials: _____ Date/Time:_____

**(YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY. YOU MAY SIGN IT IN THE PRESENCE OF TWO COMPETENT ADULT WITNESSES OR YOU MAY SIGN IT AND HAVE YOUR SIGNATURE ACKNOWLEDGED BEFORE A NOTARY PUBLIC.)**

**SIGNATURE IN PRESENCE OF TWO COMPETENT ADULT WITNESSES**

I sign my name to this *Medical Power of Attorney* on the_____day of

_____, _____, at _____, _____.
(month) (year) (city) (state)

_____
(signature)

_____
(print name)

***STATEMENT OF FIRST WITNESS:***

I am not the person appointed as agent by this document. I am not related to the principal by blood or marriage. I would not be entitled to any portion of the principal's estate on the principal's death. I am not the attending physician of the principal or an employee of the attending physician. I have no claim against any portion of the principal's death. Furthermore, if I am an employee of a health care facility in which the principal is a patient, I am not involved in providing direct patient care to the principal and am not an officer, director, partner, or business employee of the health care facility or of any parent organization of the health care facility.

Signature: _____

Print Name: _____

Address:_____ Date: _____

***SECOND WITNESS:***

Signature: _____

Print Name: _____

Address:_____ Date: _____

Initials: _____ Date/Time:_____

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

***OR***
***SIGNATURE ACKNOWLEDGED BEFORE NOTARY***

I sign my name to this *Medical Power of Attorney* on _____ day of

_____, _____, at _____, _____.
(month) (year) (city) (state)

_____
(signature)

_____
(print name)

State of Texas
County of _____

This instrument was acknowledged before me on _____ (date)

by_____(name of person acknowledging).

_____ NOTARY PUBLIC, State of Texas

Notary's printed name:_____

My commission expires: _____

Initials: _____ Date/Time:_____

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PATIENT:
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LOCATION:
PRINT DATE: SEX: FC:

# Directive To Physicians and Family Or Surrogates (Living Will)

**INSTRUCTIONS FOR COMPLETING THIS DOCUMENT:** This is an important legal document known as an Advance Directive. It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. These wishes are usually based on personal values, goals and beliefs. In particular, you may want to consider what burdens or hardships of treatment you would be willing to accept, for a particular amount of benefit obtained, if you were seriously ill. You are encouraged to discuss your values and wishes with your family or chosen spokesperson, as well as your physician. Your physician, other health care provider, or medical institution may provide you with various resources to assist you in completing your Advance Directive. Brief definitions are listed below and may aid you in your discussions and advance care planning.

**Initial the treatment choices that best reflect your personal preferences.** Provide a copy of your Directive to your physician, usual hospital, and family or spokesperson. Consider a periodic review of this document to better assure that the Directive reflects your most current preferences. In addition to this Advance Directive, Texas law provides for two other types of Directives that can be important during a serious illness. These are the *Medical Power of Attorney* and the *Out-of-Hospital Do-Not-Resuscitate Order.* You may wish to discuss these with your physician, family, hospital representative, or other advisors. You may also wish to complete a Directive related to the donation of organs and tissues.

**See Definitions with explanations on page 5.**

***DIRECTIVE***

I,_____, recognize that the best health care is based upon a partnership of trust and communication with my physician. My physician and I will make health care decisions together as long as I am of sound mind and able to make my wishes known. If there comes a time that I am unable to make medical decisions about myself because of illness or injury, I direct that the following treatment preferences be honored:

If, in the judgment of my physician, I am suffering with a terminal condition from which I am expected to die within six months, even with available life-sustaining treatment provided in accordance with prevailing standards of medical care:

_____ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; or

_____ I request that I be kept alive in this terminal condition using available life-sustaining treatment. (This selection does not apply to hospice care.)

Initials: _____ Date/Time:_____

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

If, in the judgment of my physician, I am suffering with an irreversible condition so that I cannot care for myself or make decisions for myself and am expected to die without life-sustaining treatment provided in accordance with prevailing standards of care:

_____ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld and my physician allow me to die as gently as possible; or

_____ I request that I be kept alive in this irreversible condition using available life-sustaining treatment. (This selection does not apply to hospice care.)

Additional requests: (After discussion with your physician, you may wish to consider listing particular treatments in this space that you do or do not want in specific circumstances, such as artificial nutrition and fluids, intravenous antibiotics, etc. Be sure to state whether you do or do not want the particular treatment.)

_____

_____

_____

After signing this directive, if my representative or I elect hospice care, I understand and agree that only those treatments needed to keep me comfortable would be provided and I would not be given available life-sustaining treatments. If I do not have a *Medical Power of Attorney,* and I am unable to make my wishes known, I designate the following person(s) to make treatment decisions with my physician compatible with my personal values:

1. _____

2. _____

(If a *Medical Power of Attorney* has been executed, then an agent has already been named and you should not list additional names above in this document.) If the above persons are not available, or if I have not designated a spokesperson, I understand that a spokesperson will be chosen for me following standards specified in the laws of Texas.

If, in the judgment of my physician, my death is imminent within minutes to hours, even with the use of all available medical treatment provided within the prevailing standard of care, I acknowledge that all treatments may be withheld or removed except those needed to maintain my comfort. I understand that under Texas law this directive has no effect if I have been diagnosed as pregnant. This directive will remain in effect until I revoke it. No other person may do so.

Initials: _____ Date/Time:_____

**(YOU MUST DATE AND SIGN THIS LIVING WILL. YOU MAY SIGN IT IN THE PRESENCE OF TWO COMPETENT ADULT WITNESSES OR YOU MAY SIGN IT AND HAVE YOUR SIGNATURE ACKNOWLEDGED BEFORE A NOTARY PUBLIC.)**

**SIGNATURE IN PRESENCE OF TWO COMPETENT ADULT WITNESSES**

Signed: _____ Date: _____

City, County, State of Residence: _____

Two competent adult witnesses must sign below, acknowledging the signature of the declarant. The witness designated as Witness 1 may not be a person designated to make a treatment decision for the patient and may not be related to the patient by blood or marriage. This witness may not be entitled to any part of the estate and may not have a claim against the estate of the patient. This witness may not be the attending physician or an employee of the attending physician. If this witness is an employee of a health care facility in which the patient is being cared for, this witness may not be involved in providing direct patient care to the patient. This witness may not be an officer, director, partner, or business office employee of a health care facility in which the patient is being cared for or of any parent organization of the health care facility.

***WITNESS 1***

Signature: _____

Print Name: _____

Address: _____ Date: _____

***WITNESS 2***

Signature: _____

Print Name: _____

Address: _____ Date: _____

Initials: _____ Date/Time: _____

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

***OR***
***SIGNATURE ACKNOWLEDGED BEFORE NOTARY***

I sign my name to this Living Will on _____ day of

_____, _____, at _____, _____.
(month) (year) (city) (state)

_____
(signature)

_____
(print name)

State of Texas
County of _____

This instrument was acknowledged before me on _____ (date)

by_____(name of person acknowledging).

_____ NOTARY PUBLIC, State of Texas

Notary's printed name: _____

My commission expires: _____

Initials: _____ Date/Time:_____

PATIENT:
MDA MRN: DOB:
LOCATION:
PRINT DATE: SEX: FC:

# Definitions

**Artificial Nutrition and Hydration** means the provision of nutrients or fluids by a tube inserted in a vein, under the skin in the subcutaneous tissues, or in the stomach (gastrointestinal tract).

**Irreversible Condition** means a condition, injury, or illness:
1. That may be treated, but is never cured or eliminated;
2. That leaves a person unable to care for or make decisions for the person's own self; and
3. That, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.

***Explanation:*** Many serious illnesses such as cancer, failure of a major organ (kidney, heart, liver, or lung), and serious brain disease such as Alzheimer's Dementia may be considered irreversible early on. There is no cure. But the patient may be kept alive for prolonged periods of time if the patient receives life-sustaining treatments. Late in the course of the same illness, the disease may be considered terminal when, even with treatment, the patient is expected to die. You may wish to consider which burdens of treatment you would be willing to accept in an effort to achieve a particular outcome. This is a very personal decision that you may wish to discuss with your physician, family, or other important persons in your life.

**Life-sustaining treatment** means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support such as mechanical breathing machines, kidney dialysis treatment, and artificial hydration and nutrition. The term does not include the administration of pain management medication, the performance of a medical procedure necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

**Terminal condition** means an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death within six months, even with available life-sustaining treatment provided in accordance with the prevailing standard of medical care.

***Explanation:*** Many serious illnesses may be considered irreversible early in the course of the illness, but they may not be considered terminal until the disease is fairly advanced. In thinking about terminal illness and its treatment, you again may wish to consider the relative benefits and burdens of treatment and discuss your wishes with your physician, family, or other important persons in your life.

Initials: _____ Date/Time:_____

MD Anderson Cancer Center
Making Cancer History®

# Appointment for Disposition of Remains

**Institutional**

PATIENT:
MDA MRN: CSN:
ACCT#: DOB:
ADM DATE: LOCATION:
DISCHARGE DATE: SEX: FC:
PRINT DATE: 1/14/2020;

I, _____
*(Your name and address)*

being of sound mind, willfully and voluntarily make known my desire that, upon my death, the disposition of my remains shall be controlled by _____
*(Name of Agent)*

in accordance with Section 711.002 of the Health and Safety Code and, with respect to that subject only, I hereby appoint such person as my agent (attorney-in-fact).

All decisions made by my agent with respect to the disposition of my remains, including cremation, shall be binding.

SPECIAL DIRECTIONS:

Set forth below are any special directions limiting the power granted to my agent:

_____

_____

_____

_____

AGENT:

Name: _____

Address: _____

Telephone Number: _____

SUCCESSORS:

If my agent or a successor agent dies, becomes legally disabled, resigns, or refuses to act, or if I divorce my agent or successor agent and this instrument does not state that the divorced agent or successor agent continues to serve after my divorce from that agent or successor agent, I hereby appoint the following persons (each to act alone and successively, in the order named) to serve as my agent (attorney-in-fact) to control the disposition of my remains as authorized by this document:

1. First Successor:
   Name: _____
   Address: _____
   Telephone Number: _____

# Appointment for Disposition of Remains



**Institutional**

2. Second Successor:
   Name: _____
   Address: _____
   Telephone Number: _____

DURATION:

This appointment becomes effective upon my death.

PRIOR APPOINTMENTS REVOKED:

I hereby revoke any prior appointment of any person to control the disposition of my remains.

RELIANCE:

I hereby agree that any cemetery organization, business operating a crematory or columbarium or both, funeral director or embalmer, or funeral establishment who receives a copy of this document may act under it. Any modification or revocation of this document is not effective as to any such party until that party receives actual notice of the modification or revocation. No such party shall be liable because of reliance on a copy of this document

ASSUMPTION:

THE AGENT, AND EACH SUCCESSOR AGENT, BY ACCEPTING THIS APPOINTMENT, ASSUMES THE OBLIGATIONS PROVIDED IN, AND IS BOUND BY THE PROVISIONS OF, SECTION 711.022 OF THE HEALTH AND SAFETY CODE.

SIGNATURES:

This written instrument and my appointments of an agent and any successor agent in this instrument are valid without the signature of my agent and my successor agents below. Each agent, or a successor agent, acting pursuant to this appointment must indicate acceptance of the appointment by signing below before acting as my agent.

Signed this _____ day of _____, 20___.

_____

*(Your Signature)*

MD Anderson Cancer Center
Making Cancer History®

# Appointment for Disposition of Remains

**Institutional**

PATIENT:
MDA MRN: CSN:
ACCT#: DOB:
ADM DATE: LOCATION:
DISCHARGE DATE: SEX: FC:
PRINT DATE: 1/14/2020;

State of _____

County of _____

This document was acknowledged before me on _____ *(date)*
by _____ *(Name of Principal).*

*(Seal, if any, of Notary)*

_____
*(Signature of Notarial Officer)*

My commission expires: _____

_____
*(Printed Name)*

ACCEPTANCE AND ASSUMPTION BY AGENT:

I have no knowledge of or any reason to believe this Appointment for Disposition of Remains has been revoked. I hereby accept the appointment made in this instrument with the understanding that I will be individually liable for the reasonable cost of the decedent's nterment, for which I may seek reimbursement from the decedent's estate.

Acceptance of Appointment:

_____
*(Signature of Agent)*

Date/Time of Signature: _____

Acceptance of Appointment:

_____
*(Signature of First Successor)*

Date/Time of Signature: _____

Acceptance of Appointment:

_____
*(Signature of Second Successor)*

Date/Time of Signature: _____

Figure: 25 TAC §157.25 (h)(2)

# OUT-OF-HOSPITAL DO-NOT-RESUSCITATE (OOH-DNR) ORDER

Print form

## TEXAS DEPARTMENT OF STATE HEALTH SERVICES

STOP DO NOT RESUSCITATE

This document becomes effective immediately on the date of execution for health care professionals acting in out-of-hospital settings. It remains in effect until the person is pronounced dead by authorized medical or legal authority or the document is revoked. Comfort care will be given as needed.

Person's full legal name _____ Date of birth _____ ☐ Male ☐ Female

**A. Declaration of the adult person:** I am competent and at least 18 years of age. **I direct that none of the following resuscitation measures be initiated or continued for me: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Person's signature _____ Date _____ Printed name _____

**B. Declaration by legal guardian, agent or proxy on behalf of the adult person who is incompetent or otherwise incapable of communication:**

I am the: ☐ legal guardian; ☐ agent in a Medical Power of Attorney; OR ☐ proxy in a directive to physicians of the above-noted person who is incompetent or otherwise mentally or physically incapable of communication.

Based upon the known desires of the person, or a determination of the best interest of the person, **I direct that none of the following resuscitation measures be initiated or continued for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Signature _____ Date _____ Printed name _____

**C. Declaration by a qualified relative of the adult person who is incompetent or otherwise incapable of communication:** I am the above-noted person's:

☐ spouse, ☐ adult child, ☐ parent, OR ☐ nearest living relative, and I am qualified to make this treatment decision under Health and Safety Code §166.088.

To my knowledge the adult person is incompetent or otherwise mentally or physically incapable of communication and is without a legal guardian, agent or proxy. Based upon the known desires of the person or a determination of the best interests of the person, **I direct that none of the following resuscitation measures be initiated or continued for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Signature _____ Date _____ Printed name _____

**D. Declaration by physician based on directive to physicians by a person now incompetent or nonwritten communication to the physician by a competent person:** I am the above-noted person's attending physician and have:

☐ seen evidence of his/her previously issued directive to physicians by the adult, now incompetent; OR ☐ observed his/her issuance before two witnesses of an OOH-DNR in a nonwritten manner.

**I direct that none of the following resuscitation measures be initiated or continued for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Attending physician's signature _____ Date _____ Printed name _____ Lic# _____

**E. Declaration on behalf of the minor person:** I am the minor's: ☐ parent; ☐ legal guardian; OR ☒ managing conservator.

A physician has diagnosed the minor as suffering from a terminal or irreversible condition. **I direct that none of the following resuscitation measures be initiated or continued for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Signature _____ Date _____

Printed name _____

**TWO WITNESSES:** (See qualifications on backside.) We have witnessed the above-noted competent adult person or authorized declarant making his/her signature above and, if applicable, the above-noted adult person making an OOH-DNR by nonwritten communication to the attending physician.

Witness 1 signature _____ Date _____ Printed name _____

Witness 2 signature _____ Date _____ Printed name _____

**Notary in the State of Texas and County of** _____. The above noted person personally appeared before me and signed the above noted declaration on this date: _____

Signature & seal: _____ Notary's printed name: _____ *Notary Seal*

**[ Note: Notary cannot acknowledge the witnessing of the person making an OOH-DNR order in a nonwritten manner ]**

**PHYSICIAN'S STATEMENT:** I am the attending physician of the above-noted person and have noted the existence of this order in the person's medical records. **I direct health care professionals acting in out-of-hospital settings, including a hospital emergency department, not to initiate or continue for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Physician's signature _____ Date _____

Printed name _____ License # _____

**F. Directive by two physicians on behalf of the adult, who is incompetent or unable to communicate and without guardian, agent, proxy or relative:** The person's specific wishes are unknown, but resuscitation measures are, in reasonable medical judgment, considered ineffective or are otherwise not in the best interests of the person. **I direct health care professionals acting in out-of-hospital settings, including a hospital emergency department, not to initiate or continue for the person: cardiopulmonary resuscitation (CPR), transcutaneous cardiac pacing, defibrillation, advanced airway management, artificial ventilation.**

Attending physician's signature _____ Date _____ Printed name _____ Lic# _____

Signature of second physician _____ Date _____ Printed name _____ Lic# _____

Physician's electronic or digital signature must meet criteria listed in Health and Safety Code §166.082(c).

**All persons who have signed above must sign below, acknowledging that this document has been properly completed.**

Person's signature _____ Guardian/Agent/Proxy/Relative signature _____

Attending physician's signature _____ Second physician's signature _____

Witness 1 signature _____ Witness 2 signature _____ Notary's signature _____

***This document or a copy thereof must accompany the person during his/her medical transport.***

# INSTRUCTIONS FOR ISSUING AN OOH-DNR ORDER

**PURPOSE:** The Out-of-Hospital Do-Not-Resuscitate (OOH-DNR) Order on reverse side complies with Health and Safety Code (HSC), Chapter 166 for use by qualified persons or their authorized representatives to direct health care professionals to forgo resuscitation attempts and to permit the person to have a natural death with peace and dignity. This Order does NOT affect the provision of other emergency care, including comfort care.
**APPLICABILITY:** This OOH-DNR Order applies to health care professionals in out-of-hospital settings, including physicians' offices, hospital clinics and emergency departments.
**IMPLEMENTATION:** A competent adult person, at least 18 years of age, or the person's authorized representative or qualified relative may execute or issue an OOH-DNR Order. The person's attending physician will document existence of the Order in the person's permanent medical record. The OOH-DNR Order may be executed as follows:
**Section A** - If an adult person is competent and at least 18 years of age, he/she will sign and date the Order in Section A.
**Section B** - If an adult person is incompetent or otherwise mentally or physically incapable of communication and has either a legal guardian, agent in a medical power of attorney, or proxy in a directive to physicians, the guardian, agent, or proxy may execute the OOH-DNR Order by signing and dating it in Section B.
**Section C** - If the adult person is incompetent or otherwise mentally or physically incapable of communication and does not have a guardian, agent, or proxy, then a qualified relative may execute the OOH-DNR Order by signing and dating it in Section C.
**Section D** - If the person is incompetent and his/her attending physician has seen evidence of the person's previously issued proper directive to physicians or observed the person competently issue an OOH-DNR Order in a nonwritten manner, the physician may execute the Order on behalf of the person by signing and dating it in Section D.
**Section E** - If the person is a **minor** (less than 18 years of age), **who has been diagnosed by a physician as suffering from a terminal or irreversible condition**, then the minor's parents, legal guardian, or managing conservator may execute the OOH-DNR Order by signing and dating it in Section E.
**Section F** - If an adult person is incompetent or otherwise mentally or physically incapable of communication and does not have a guardian, agent, proxy, or available qualified relative to act on his/her behalf, then the attending physician may execute the OOH-DNR Order by signing and dating it in Section F with concurrence of a second physician (signing it in Section F) who is not involved in the treatment of the person or who is a representative of the ethics or medical committee of the health care facility in which the person is a patient.
**In addition**, the OOH-DNR Order must be signed and dated by two competent adult witnesses, who have witnessed either the competent adult person making his/her signature in section A, or authorized declarant making his/her signature in either sections B, C, or E, and if applicable, have witnessed a competent adult person making an OOH-DNR Order by nonwritten communication to the attending physician, who must sign in Section D and also the physician's statement section. Optionally, a competent adult person or authorized declarant may sign the OOH-DNR Order in the presence of a notary public. However, a notary cannot acknowledge witnessing the issuance of an OOH-DNR in a nonwritten manner, which must be observed and only can be acknowledged by two qualified witnesses. Witness or notary signatures are not required when two physicians execute the OOH-DNR Order in section F. The original or a copy of a fully and properly completed OOH-DNR Order or the presence of an OOH-DNR device on a person is sufficient evidence of the existence of the original OOH-DNR Order and either one shall be honored by responding health care professionals.
**REVOCATION:** An OOH-DNR Order may be revoked at ANY time by the person, person's authorized representative, or physician who executed the order. Revocation can be by verbal communication to responding health care professionals, destruction of the OOH-DNR Order, or removal of all OOH-DNR identification devices from the person.
**AUTOMATIC REVOCATION:** An OOH-DNR Order is automatically revoked for a person known to be pregnant or in the case of unnatural or suspicious circumstances.

## DEFINITIONS

**Attending Physician:** A physician, selected by or assigned to a person, with primary responsibility for the person's treatment and care and is licensed by the Texas Medical Board, or is properly credentialed and holds a commission in the uniformed services of the United States and is serving on active duty in this state**.** [HSC §166.002(12)].
**Health Care Professional:** Means physicians, nurses, physician assistants and emergency medical services personnel, and, unless the context requires otherwise, includes hospital emergency department personnel. [HSC §166.081(5)]
**Qualified Relative:** A person meeting requirements of HSC §166.088. It states that an adult relative may execute an OOH-DNR Order on behalf of an adult person who has not executed or issued an OOH-DNR Order and is incompetent or otherwise mentally or physically incapable of communication and is without a legal guardian, agent in a medical power of attorney, or proxy in a directive to physicians, and the relative is available from one of the categories in the following priority: 1) person's spouse; 2) person's reasonably available adult children; 3) the person's parents; or, 4) the person's nearest living relative. Such qualified relative may execute an OOH-DNR Order on such described person's behalf.
**Qualified Witnesses:** Both witnesses must be competent adults, who have witnessed the competent adult person making his/her signature in section A, or person's authorized representatives making his/her signature in either Sections B, C, or E on the OOH-DNR Order, or if applicable, have witnessed the competent adult person making an OOH-DNR by nonwritten communication to the attending physician, who signs in Section D. Optionally, a competent adult person, guardian, agent, proxy, or qualified relative may sign the OOH-DNR Order in the presence of a notary instead of two qualified witnesses. Witness or notary signatures are not required when two physicians execute the order by signing Section F. One of the witnesses must meet the qualifications in HSC §166.003(2), which requires that at least one of the witnesses not: (1) be designated by the person to make a treatment decision; (2) be related to the person by blood or marriage; (3) be entitled to any part of the person's estate after the person's death either under a will or by law; (4) have a claim at the time of the issuance of the OOH-DNR against any part of the person's estate after the person's death; or, (5) be the attending physician; (6) be an employee of the attending physician or (7) an employee of a health care facility in which the person is a patient if the employee is providing direct patient care to the patient or is an officer, director, partner, or business office employee of the health care facility or any parent organization of the health care facility.
***Report problems with this form to the Texas Department of State Health Services (DSHS)*** or order OOH-DNR Order/forms or identification devices at (512) 834-6700.

*Declarant's, Witness', Notary's, or Physician's electronic or digital signature must meet criteria outlined in HSC §166.011*