Advance Care Planning

THE UNIVERSITY OF TEXAS
MD Anderson
~~Cancer~~ Center

Making Cancer History®

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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.

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 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.

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?

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

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

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

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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: ______________________________

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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: ______________________________

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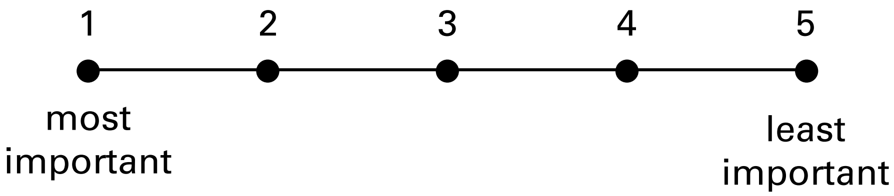

Thinking About the End of Life

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?

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

- ☐ Visit with family and friends.
- ☐ 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.
- ☐ Travel to: ______________________________
- ☐ 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 nutrition
- Artificial hydration (fluids)
- 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 **Artificial Nutrition** 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 **Artificial Nutrition** (Fluids) in **Appendix A** to learn about the different types of artificial hydration:

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

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

What are your thoughts and preferences 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?

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

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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 or 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?

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

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Questions to Ask Your Doctor

There are many medical situations for you to consider. These may include your symptoms, side effects of treatment or changing the goal of your treatment. 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 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 choices if I stop treatment or choose not to pursue further treatment?

Questions About Side Effects

- Can I expect any lasting 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?

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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."

Notes

Record Your Medical Wishes

Documents

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 signed correctly.

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 (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 (This is a medical order.)	None

Consider the following tips as you work through your documents:

- When you have chosen a medical power of attorney, make sure to include the person 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 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 your medical team.

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 they think 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.

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 end of life. It addresses the use of comfort care and life-sustaining treatments (such as artificial nutrition, hydration, dialysis, and breathing support).

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

If you sign a 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 cardiopulmonary resuscitation (CPR).

A DNR order only addresses the use of CPR. If your health care team 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, a health care team 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 doctor 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.

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 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 following 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: Box #: 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		
Instagram		

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 through your actions, values and shared memories. 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 times 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 or 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 an end of your life. It is a way to engage with the people you care about at any stage of your life. 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.

Decreased Energy

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

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.

Inability to Write

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

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

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

Voice

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.

Notes

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 being connected to themselves, others, nature 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?

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

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Do you have a spiritual community, advisor or representative?

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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 or sorority or other special requests.

Contact information for funeral home or service location:

____

____

I wish to be:

☐ **Buried**

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 or tissue. This is also subject to the acceptance criteria of medical institutions. In Texas, for example, you may visit 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.

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Obituary Writing

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

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

Notes

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 workbook.

- 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 a social work counselor, call **713-792-6195**.

How Chaplains Can Help

Chaplains are available to assist people from all faith backgrounds. They can help you:

- Clarify your values and beliefs.
- Understand your options.
- Have difficult conversations about your end of life wishes.
- With spiritual or religious questions or concerns.
- Plan and prepare final arrangements. Chaplains can also provide end of life rituals, prayers and sacraments.
- 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 speak up 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.

Talking With Children

Honest information is best for children. It is important 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 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 a social work counselor, chaplain or supportive care team.

Read more about advance care planning online at MDAnderson.org/AdvanceCarePlanning.

Notes

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 (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. 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. Talk with your health care team about artificial hydration before you need it.

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 not all health care teams may 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 as needed.

Complications may include:

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

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.

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