

ADVANCE CARE PLANNING • ADVANCE DIRECTIVE

The Gift of Having the **CONVERSATION**

HOW TO SPEAK TO LOVED ONES ABOUT HEALTHCARE WISHES

QUESTIONS?

Please contact the **Palliative Care Team**
at Midland Memorial Hospital

432.221.4212

midlandhealth.org



Facts about end-of-life wishes

Why talking matters

{ 90% of people say that talking with their loved ones about end-of-life care is important
27% have actually done so*

{ 60% of people say that making sure their family is not burdened by decisions is extremely important
56% have not communicated their end-of-life wishes**

{ 80% of people say that if they are seriously ill, they would talk to their physician about wishes for medical treatment toward the end of their life
7% report actually having this conversation with their physician

{ 82% of people say it's important to put their wishes in writing
23% have actually done it**

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* Source: *The Conversation Project National Survey (2013)*

** Source: *Survey of Californians by the California Healthcare Foundation (2012)*



**WHAT ARE THE THINGS
THAT MATTER MOST?**

Basics of Advance Care Directives

Advance Care Planning is the process of having conversations with your family, physicians, and possibly spiritual leaders about what quality of life means to you at the end of life. An advance directive is the legal document where you designate your healthcare preferences AND your healthcare agent. This is the person you choose to speak for you if you are no longer able to communicate.

BEGIN THE CONVERSATION

Advance Care Planning (ACP) and Advance Directives (AD), accomplish several goals of good healthcare. Together, the two:

- Build trust between doctor, patient, and healthcare agent
- Help to ensure that the patient's healthcare wishes will be honored
- Help to reduce stress and anxiety for loved ones
- Help to avoid confusion and conflict
- Promote peace of mind, and remind us of what is really important in our lives

WHY TALK ABOUT ADVANCE CARE PLANNING AND ADVANCED DIRECTIVES?

Discussing healthcare wishes with family members and physicians:

- Clarify the patient's preferences
- Support the patient's loved ones in making difficult decisions by eliminating doubt and lessening pain
- May eliminate the financial burden of futile care
- Often creates more closeness in families
- Gives everyone time to process important information regarding end-of-life care BEFORE a medical crisis arises



Re-Examine Advance Directives
when the 5 D's occur

DECADE • DEATH • DIVORCE
DIAGNOSIS • DECLINE

FAQs on Advance Care Directives

WHAT IS AN ADVANCE DIRECTIVE?

An advance care directive is a legal document that specifies two very important things:

1. In what has also been called a **living will**, an advance directive allows us to document, in writing, our end-of-life healthcare choices in the event we are no longer able to communicate. In other words—what is the medical treatment we would or would not want if we had an irreversible condition or were close to death?
2. An advance directive also allows us to designate a healthcare agent. This is the person the patient chooses to communicate our wishes to medical staff AND ensure that health care choices are honored. A legally-designated healthcare agent is not restricted by HIPPA laws.

WHY IS IT IMPORTANT TO HAVE AN ADVANCE DIRECTIVE?

If having choices of the medical treatment that we do, or do not want at the end of our lives is a priority to us, then it is important that we take responsibility by sharing with our loved ones and talking about what is important to us.

An advance directive does not take effect until a physician and another member of the medical staff determines a that patient no longer has the capacity to make their own healthcare decisions.

WHAT IS THE ROLE OF A HEALTHCARE AGENT?

A healthcare agent is the person designated to make healthcare decisions for a loved one, family member, or friend when that person can no longer make his or her own decisions. Other names for this healthcare agent are durable power of attorney for healthcare, surrogate decision-maker, or healthcare proxy.

WHO CANNOT SERVE AS A HEALTHCARE AGENT?

- Anyone younger than 18 years old
- A healthcare provider, or the employee of the healthcare provider
- The owner or operator of a healthcare or residential facility where the patient is being cared for

WHAT ARE QUALITIES OF A GOOD HEALTHCARE AGENT?

- A good healthcare agent is a trusted individual who knows the values, goals, beliefs, and healthcare preferences of the person on whose behalf they are making medical care decisions.
- A good healthcare agent is someone who can honor another's wishes even when he/she does not personally agree with them.
- A good healthcare agent is someone who listens well and asks good questions.
- A good healthcare agent will not be overcome with emotions that would hinder good decision-making.
- A good healthcare agent should be able to answer **yes** to the following questions:
 - Do I know this person's goals, values, beliefs and healthcare preferences?
 - Can I honor decisions they would make, even if I wouldn't make the same ones for myself?
 - Can I make hard decisions in stressful situations?
 - Am I willing to take on the responsibility of this role?

HOW TO BE THE BEST HEALTHCARE AGENT YOU CAN BE

Being a healthcare agent is one of the most precious gifts you can give someone who trusts you to make important and often difficult medical decisions.

Prior to a health crisis, ask the person to explain the treatment they would want or not want to prolong life if he/she...

- Can no longer think for him/herself
- Can no longer communicate
- Can no longer recognize loved ones
- Is terminally ill and very near death
- Is unlikely to regain consciousness

Have good conversations with the person you are willing to represent. Be willing to have more than one conversation on more than one occasion as planning takes thought and time.

Ask good questions:

- What does "quality of life" mean to you?
- Under what circumstances would you consider living to be worse than dying?
- What is the minimum degree of life quality that would be tolerable to you?
- At what point would you wish to be allowed to die a natural death?

Ask for explanations of statements you don't understand like "I don't want to be a vegetable" or "just pull the plug."

Understand the person's desired goals of medical care.

Keep a copy of the completed advance directive where you are named as the healthcare agent, and thoroughly review, understand, and discuss its contents before putting it away.

WILL MY ADVANCE DIRECTIVE BE HONORED IN AN EMERGENCY?

Generally, the answer to this question depends on several other questions.

- Have I had the crucial conversations with those who will be involved? Are my family members clear about what I want or don't want?
- Are my loved ones and friends in agreement to honor my wishes and support the person chosen as my healthcare agent?
- Is my agent prepared to advocate and stand firm, under what may be a highly-emotional and stressful event? Can my agent respond quickly and clearly under stress? Is my agent capable of standing up to emotional family members and/or physicians, if necessary, to ensure that my healthcare preferences are honored?

WILL MY ADVANCE DIRECTIVE BE HONORED IN ANOTHER STATE?

Many states' laws explicitly honor out-of-state directives as long as they do not conflict with that state's own law. A state would probably honor an advance directive that clearly expresses treatment wishes. We have constitutional and common-law rights to accept or refuse treatments, and this may be broader than

PEACE
of **MIND**
FOR YOU AND THOSE YOU LOVE

rights under a specific state law. If significant time is spent in more than one state, we recommend advance directives be completed for the state involved.

IF I SIGN AN ADVANCE DIRECTIVE, WILL DOCTORS STILL TAKE CARE OF ME IF I'M SICK?

Yes, a doctor or hospital cannot condition treatment on whether or not there is an advance directive. Even if the patient declines certain kinds of treatment, one may need care to ensure that the patient is kept comfortable and free of pain.

WHAT DO I DO IF I DON'T WANT CPR WHEN AN AMBULANCE IS CALLED?

Ask how to get an Out-of-Hospital DNR order. This may also be called a Comfort Care Only order. These usually require a physician's signature and your consent. Additionally, make clear to family and the healthcare agent that NO CPR is your preference.

WHAT ARE CONSIDERED LIFE-SUSTAINING PROCEDURES?

Artificial nutrition/hydration through a tube or central line, cardiopulmonary resuscitation (CPR), being placed on a ventilator, having dialysis, defibrillation, antibiotics, and surgery—unless it is performed to ensure comfort.

HOW DO I CHANGE AN ADVANCE DIRECTIVE?

- Complete a new advance directive. It is best not to make any changes unless a new directive is completed.
- Destroy all copies of your old advance directive.
- Make sure your agent, family, and doctor know about your new wishes, and give them a copy of the new directive.

HOW DO I MAKE MY ADVANCE DIRECTIVE LEGAL?

One of two options is to have it witnessed by two people who are:

- 18 years or older
- Not the person's healthcare provider or provider employees
- Not designated as the person's healthcare agent
- Not financially responsible for the person's healthcare

- Not an employee of a life or health insurance provider for the person
- Not related to the person by blood, marriage, or adoption
- Not going to benefit, in any way, from the estate.

The other option is to have the advance directive notarized.

WHO SHOULD COMPLETE AN ADVANCE DIRECTIVE?

Everyone age 18 and older should have an advance directive. Accidents are the leading cause of death for ages 18-40 years old.

WHAT SHOULD I DO WITH MY ADVANCE DIRECTIVE AFTER IT IS SIGNED?

Make several photocopies of the completed document. Keep the original in a safe but accessible place (not a safe deposit box). Give a copy to the agent, alternate agent, the doctor, and anyone else who might be involved with your healthcare. Ask that a copy be included in your electronic health record.

WHEN SHOULD I RE-EXAMINE MY ADVANCE DIRECTIVE?

Whenever any of the "five Ds" occur:

- 1. DECADE** | Each new decade of your life.
- 2. DEATH** | Whenever you experience the death of a loved one.
- 3. DIVORCE** | If you experience a divorce or other major family change.
- 4. DIAGNOSIS** | If you are diagnosed with a serious health condition.
- 5. DECLINE** | When you experience a significant decline or deterioration of an existing health condition—especially if it decreases your independence.

WHERE DO I OBTAIN THE DOCUMENT?

You can contact Midland Memorial Hospital at **432.221.4212** and we will help you obtain the Advance Directive packet, or scan the QR code to complete one online through **mydirectives.com**.



Build trust. Help to ensure healthcare wishes are honored.



Advance Directives: Values Clarification Worksheet

Although it would be difficult to anticipate every possible medical crisis where an advance directive would be needed, this worksheet may help clarify what quality of life means to you.

PART 1: QUALITY OF LIFE | *I want my healthcare provider to try treatments that may return me to an acceptable quality of life and allow me to do the things that are important to me.*

ACTIVITIES OF DAILY LIFE	LEVEL OF IMPORTANCE			
	VERY	SOMEWHAT	UNIMPORTANT	NOT SURE
Able to recognize my friends and family				
Able to talk and be understood				
Able to think clearly				
Being pain free				
Free of severe discomfort most of the time (such as nausea, diarrhea, or shortness of breath)				
Able to feed myself				
Able to control my bowels				
Living in my own home				

PART 2: HOPE FOR RECOVERY OR NATURAL DEATH | *If I were very sick—told that I was to die soon—and there was no reasonable hope that I would regain a quality of life acceptable to me:*

	YES	NO	NOT SURE
I would want all possible treatments, even though my healthcare providers don't think they could help me			
I would expect to be given care and treatment for pain or discomfort even when such care might shorten my life, make me feel like not eating, or slow down my breathing			

PART 2: HOPE FOR RECOVERY OR NATURAL DEATH (CONT'D) | *If I were in a coma and the healthcare provider thought I have only a slight change of returning to my previous level of functioning:*

	YES	NO	NOT SURE
I would want to be kept alive indefinitely			
I would not want to be given treatment just to keep me alive when I had a condition that would cause me to die soon			
I would not want to be given a treatment to keep me alive if I had a condition so bad (including substantial brain damage or brain disease) that there was no reasonable hope that I would regain a quality of life acceptable to me			

PART 3: PERSONAL AND SPIRITUAL BELIEFS | *What are the personal, ethical, religious, or spiritual beliefs you want respected in decision-making about life-sustaining treatments?*

	YES	NO	NOT SURE
It is always wrong to withhold (not start) treatments that could keep me alive			
It is always wrong to withdraw (stop) treatments that could keep me alive			
It is wrong to withhold (not provide) nutrition and fluids given through tubes, even if I am terminally ill or in a permanent coma			
I do not wish to receive a blood transfusion of any blood products, such as plasma or red blood cells			

PART 4: TREATMENTS I DO NOT WANT | *When I have one of the listed conditions, the treatments I DO NOT want include:*

I DO NOT WANT	LISTED CONDITIONS			
	COMA	DEMENTIA	SEVERE STROKE	TERMINAL ILLNESS
Surgery (unless for comfort)				
Doing things to start my heart or breathing, if either stops (CPR)				
Medicine to treat infections (antibiotics)				
Artificial kidney machine (dialysis)				
Breathing machine (respirator, ventilator)				
Food or water given through a tube in the vein, nose, and/or stomach (tube feedings or IV)				
Chemotherapy (cancer treatment)				
Radiation (cancer treatment)				
Blood transfusions				
Other treatments:				

PART 5: HOW DO YOU WANT TO SPEND YOUR LAST DAYS?

ACTIVITIES OF DAILY LIFE	LEVEL OF IMPORTANCE			
	VERY	SOMEWHAT	UNIMPORTANT	NOT SURE
Avoiding pain and suffering, even if it means that I might not live as long				
Being alert, even if it means I might be in pain				
Being around my family and close friends				
Being able to feel someone touching me				
Having religious or spiritual advisors at my side when I die				
Being able to tell my life story and leave good memories for others				
Reconciling differences and saying “goodbye” to my family and friends				
Being at home when I die				
Being in a hospital when I die				
Being kept alive long enough for my family to get to my bedside to see me before I die, even if I'm unconscious				

PART 5 (CONT'D): MY BIGGEST HOPES ABOUT THE END OF MY LIFE ARE:

PART 5 (CONT'D): MY BIGGEST FEARS ABOUT THE END OF MY LIFE ARE:

RESOURCES:

- org.tx.us
- theconversationproject.org
- begintheconversation.org
- mydirectives.com/midland-memorial
- apps.americanbar.org/aging/publications/docs/consumer_tool_kit_bk.pdf