A Time to Act

Putting Advance Care Planning in Motion

ADVANCE CARE PLANNING GUIDE

The Jewish Federation of Fort Worth & Tarrant County
Beth-El Congregation
Congregation Ahavath Sholom
Congregation Beth Israel
Congregation Beth Shalom

Made possible by a grant from the Jewish Federation of Fort Worth & Tarrant County and support from our sponsors

Sponsors

Asana Hospice and Palliative Care
Assisted Services, Inc.
Community Hospice of Texas
Robertson Mueller Harper Funeral Directors
The Jewish Federation of Fort Worth & Tarrant County
The Stayton at Museum Way
Telschow Johnson Law PLLC
Universal Health Services
VITAS Healthcare

The Advance Care Planning Committee of Fort Worth & Tarrant County

Cantor Sheri Allen (Chair), Martha Brown, Martin Brown, Larry Goodman, Ken Licker, Melissa Morgan, Karen Telschow Johnson, Jane Oderberg, David Saul, Judith Williams, Stuart Yarus, and Bob Goldberg, Executive Director of The Jewish Federation of Fort Worth & Tarrant County

---

Material from this guide has been borrowed from the following resources, with permission from the institutions that created them. We are grateful for their assistance, and encourage you to access their websites (listed on the back page) for more detailed information about Advance Care Planning:

- *Baylor Scott & White Health: Advance Care Planning*
- *Compassion & Choices – Care and Choice at the End of Life*
- *The Conversation Project*
- *My Directives*
- *The National Hospice and Palliative Care Organization*
- *North Texas Respecting Choices*

Table of Contents

Introduction 2
Defining the Documents 3
The Advance Care Planning Process 9
Glossary of Medical Terms 18
Resources 27

Introduction

What is Advance Care Planning?

Advance care planning is the process of understanding possible future healthcare decisions; considering what you might want for yourself, taking into account your personal, cultural, religious and/or spiritual values; talking about these choices with your doctors and people close to you; and making a plan for future possible healthcare situations.

Advance care planning is important at any age. Even if you're not dealing with a life-limiting illness, an accident or injury could occur at any time. That's why it's such a good idea to talk through end-of-life decisions before a crisis arises.

This Advance Care Planning Guide is designed to help you clarify your goals and wishes regarding your future healthcare choices. The information contained in this guide should help you attain the information and peace of mind needed in order to fill out your Advance Directive documents.

Defining the Documents

ADVANCE DIRECTIVE

"Advance Directive" is a broad term used for different kinds of Advance Care Plans you make for future healthcare that expresses your goals, values, and preferences for care. It gives your doctors and family guidance in how to care for you when you cannot speak for yourself or make your wishes known to them.

* A formal, written directive is always better than nothing, but a true plan, written or unwritten, is better than document completion.
* As long as you are capable, you may change or revoke your advance directive at any time.
* It is a good idea to update your advance directive regularly, or when there are major health or life changes.
* Make copies of your advance directive, distribute them to loved ones, keep one on file with your doctor.

The plans this guide addresses specifically are:

1) Medical Power of Attorney (MPOA) or Healthcare Proxy Agent

2) Directive to Physicians or Living Will.

The following pages explain in detail what these plans entail, and will offer questions for you to think about as you begin to talk about them with your loved ones and then put those plans on paper.

Notes

Document #1:

MEDICAL POWER OF ATTORNEY/ HEALTHCARE PROXY AGENT

The Medical Power of Attorney (MPOA) or Health Care Proxy Agent (previously entitled "Durable Power of Attorney for Healthcare) allows the designated person or persons (family member, friend or anyone you trust) to make health care decisions on your behalf should you become unable to make the decisions yourself.

* He/she must be at least 18 years old
* He/she cannot be your doctor or someone who works at your hospital, clinic, home health agency, nursing home or residential care home unless they are a family member.
* If you do not complete a MPOA form, Texas law will appoint a family member to make decisions for you.
* There are two triggers for the Directive to go into effect:
    1. You can no longer make decisions for yourself *(you are unconscious)* and/or,
    2. You cannot effectively communicate with the medical staff *(you have suffered a medical event and your words are not clear)*. At the time, you are declared incompetent, and this fact is certified in writing by your physician.

* The agent has the same authority to make decisions about health care as you would have. For example, the MPOA/agent appointed may consent, refuse to consent, or withdraw consent to medical treatment, and may make decisions about withdrawing or withholding life-sustaining treatment.
* It is very important to discuss your desires regarding end-of-life decisions and the use of life-sustaining measures with the person you plan to designate as your MPOA (and alternate, if desired). Thus, instead of making decisions, *the MPOA acts as your advocate to carry out the decisions that you have already made.*
* It is not unusual for people to have difficulty choosing an agent. Some people are very clear that they want a spouse, partner, a particular family member or even friend to be their agent. Others are not sure they want to put those closest to them in the position of making these difficult decisions. Be sure both you and your agent are comfortable with your choices and that your agent understands and is willing to carry out your wishes.

Document #2:

DIRECTIVE TO PHYSICIANS OR LIVING WILL

The Directive to Physicians (also known as a "Living Will" or an "Advance Directive") is a statutory form created by the Texas legislature. This document allows you to provide instructions to your MPOA/agent regarding the types of medical treatments that you prefer under certain circumstances at the end of life.

* There are three triggers for the Directive to go into effect:
    1. You are certified in the medical record as terminally or irreversibly ill.
    2. You can no longer make decisions about your care.
    3. You are in a hospital setting.
* In preparing a Directive to Physicians/Living Will you will need to consider how you feel about end-of-life decisions and the use of life-sustaining measures such as breathing machines, kidney dialysis, and artificial nutrition/hydration. Consider what various life sustaining measures mean to you and your loved ones, and make your own decisions about what you want your Advance Directive to specify. You can also list particular treatments not wanted in specific circumstances.

Notes

The Advance Care Planning Process

The first step in planning for your end-of-life care is thinking about your choices. You need to plan for situations where you may become unexpectedly incapable of making your own decisions. Making these choices requires understanding the information, weighing the benefits and burdens from your perspective, and discussing your choices with your loved ones.

There are five steps in the process:

1. Thinking about how you would like to receive care
2. Starting a conversation with your loved ones
3. Choosing a Medical Power of Attorney/Health Care Proxy Agent
4. Starting a conversation with your doctor
5. Documenting your decisions by completing necessary forms

STEP 1:
THINKING ABOUT HOW YOU WOULD LIKE TO RECEIVE CARE:

Fill out the following Quality of Life Questionnaire in preparation to begin The Conversation with your loved ones and potential Medical Power of Attorney (MPOA):

What makes your life meaningful and worth living?
(Describe your Best Possible Day)

What sources influence your medical decision-making?
(i.e.: news coverage, religious/ethical beliefs, books/articles?)

Do you have any experience with family/friends who became seriously ill/injured? What did you learn from it?

What, if any, concerns do you have about completing your Directives?
(i.e., Medical Power of Attorney and Directive to Physicians/Living Will)

If you were to become seriously ill, *(i.e., you have a terminal or irreversible illness in which a cure or remission is no longer possible)* **what would be the goals of care?** *(Check all that apply)*

- ❑ Stay off machines
- ❑ Live as long as possible regardless of quality of life
- ❑ Be pain-free, even if that means that medicine might make you sleep more often
- ❑ Be able to breathe without difficulty
- ❑ Maintain dignity
- ❑ Have the chance to make peace/say goodbye to loved ones
- ❑ Have financial affairs or "unfinished business" in order
- ❑ Die at home
- ❑ Die in a hospital, a nursing home or long-term care facility
- ❑ Avoid unnecessary expenses for continued care
- ❑ Have others talk to you even if you are unresponsive
- ❑ Have others with you when the end is imminent
- ❑ Have prayer and/or music in your room/home
- ❑ Stay true to your spiritual beliefs/traditions

You would want your goals of care to transition from medical treatment to comfort care if: *(check all that apply)*

- ❑ You have lost your ability to communicate with, respond to, or understand others
- ❑ You are dependent on life sustaining treatments to keep you alive
  For example:
  ❑ ventilator ❑ feeding tube ❑ dialysis (kidney machines)
- ❑ You have lost control of bodily functions
- ❑ You are experiencing pain that no longer responds to medications
- ❑ You are bed-bound or confined to a wheelchair
- ❑ You are in a permanently unconscious state with no reasonable probability of recovery *(i.e., severe, permanent brain injury or stroke)*
- ❑ You would want to continue medical treatment indefinitely under any circumstances

STEP 2:
STARTING A CONVERSATION WITH YOUR LOVED ONES

* Think about a convenient time to speak individually with family members/friends, or if you prefer to have a communal conversation, call a family meeting.
* Begin by stating that although there never seems to be a good time to talk about this, you have given it a lot of thought and it's important to you.
* Explain that unless we are living with illness, we tend to avoid the subject or think it does not pertain to us. But life is unpredictable, and you can be healthy one minute, and the next minute there's a car accident and you're on life support. Suddenly, a doctor is asking your family to make hard decisions. Talking with your family now lets them know what you would want at the end of life, and can save them the emotional and spiritual distress that can emerge when the crisis is at hand.
* Discuss the answers you gave on your Quality of Life Questionnaire, and clarify any questions your family members/friends may have.
* You may even urge them to think about answering these questions for themselves if they have not done so already.

STEP 3:
CHOOSING THE PERSON TO BE YOUR MEDICAL POWER OF ATTORNEY/HEALTH CARE PROXY AGENT

Questions to ask your potential MPOA:

1. Are you willing to take on this responsibility?
2. Will you honor my decisions even if they are not what you would want?
3. Will you be available to talk to doctors to understand the treatment options available to me, and ask them for more information if you do not understand a treatment?
4. Will you be able to visit me often enough to understand my condition?
5. Will you be able to make choices in difficult moments that may require review or change?
6. Is there anything about my advance care plan that you do not understand or need clarified?
7. Are you able to verbally share my plan with others?

STEP 4:
STARTING A CONVERSATION WITH YOUR DOCTOR

Talking with your doctor or healthcare providers about your end-of-life wishes is a discussion to have before a crisis occurs. Chances are that he or she is waiting for you to start the conversation.

When you discuss your concerns and choices:

- Ask your doctor to explain treatments and procedures that may seem confusing, as well as the burdens and benefits of those treatments, before you complete your directives.
- Talk about pain management options.
- Let your doctor know that you are completing your advance directives.
- Make sure your doctor is willing to follow your directives. The law does not force physicians to follow directives if they disagree with your wishes for moral or ethical reasons.
- Give your doctor a copy of your completed directives. Make sure your doctor knows the name and telephone number of your appointed healthcare agent.
- Assure your doctor that your family and your appointed healthcare agent know your wishes.

You may ask your doctor specifically:

- Will you talk openly and candidly with me and my family about my illness?
- What decisions will my family and I have to make, and what kinds of recommendations will you give to help us make these decisions?
- What will you do if I have a lot of pain or other uncomfortable symptoms?

- How will you help us find excellent professionals with special training when we need them (e.g., medical, surgical and palliative care specialists, faith leaders, social workers, etc.)?
- Will you let me know if treatment stops working so that my family and I can make appropriate decisions?
- Will you still be available to me even when I am close to the end of my life?

STEP 5: DOCUMENTING YOUR DECISIONS BY COMPLETING NECESSARY FORMS

* Complete and sign your Medical Power of Attorney and Directive to Physicians/Living Will at the back of this guide in the presence of two witnesses. Make sure you check the stipulations in these documents to determine who may and may not serve as witnesses)
* Make copies and share them with the people who care for you: doctors, nurses, social workers, chaplains, lawyers, family, your MPOA and friends so they will know what you want. You plan should NOT be a secret to those who will be involved in your future health care.
* Keep a copy in your car in case you are ever asked to present it.
* Continue the conversation and updating your directives as your medical condition changes.

Glossary of Medical Terms

Brain Injury

There are many causes of brain injuries, including trauma, stroke, lack of oxygen, chemical imbalances, metabolic disturbances, drug overdoses, and infections. Regardless of the cause, serious brain injuries usually lead to a coma. A good way to think of coma is an "eyes-closed unconsciousness." A person in a coma appears asleep, lacks purposeful body movement, cannot communicate, and has no awareness of self or surroundings.

Almost no one stays in a coma forever. Patients may deteriorate and become brain dead or they may recover all the way back to normal. Other comatose patients may enter the vegetative state, a minimally conscious state or a locked-in state.

Vegetative State

A vegetative state is usually described as an "eyes-open unconsciousness." The patient has sleep-wake cycles and, when awake, his or her eyes will be open, but as with comatose patients, a person in a true vegetative state has no awareness of self or surroundings, no communication, and no sustained, purposeful or voluntary movement. Current neuroscience suggests that true vegetative patients do not suffer. However, at least some patients who appear vegetative on bedside exam may have some degree of consciousness detectable on more sophisticated testing. These patients can be considered minimally conscious.

Minimally Conscious State

A patient who is in a minimally conscious state may appear vegetative on initial evaluation, but a closer examination and more sophisticated testing may reveal sporadic minimal levels of consciousness. Patients in a minimally conscious state may have some limited awareness of themselves and their environment. Unfortunately, such patients may have enough consciousness to suffer, but they are unable to communicate that suffering to others.

Locked-In State

Locked-in patients are as conscious as any normal person but can move only their eyes. Such patients may clearly suffer physically, emotionally, and spiritually but can only communicate that by blinking or other eye movements in response to questions about suffering.

Doctors and nurses may be able to keep patients with serious brain injuries alive for prolonged periods of time without curing the patient. For example, although a young patient may have little chance of recovery from a vegetative, minimally conscious, or locked-in state, doctors and nurses may be able to keep the patient alive for decades.

In contrast, when a person is declared brain dead, he or she is legally dead. There is currently no treatment to reverse brain death, and there is no United States federal or state law that prohibits the removal or withholding of treatments that support other organs in brain dead patients.

Comfort Care

According to the National Institute on Aging, "An essential part of medical care at the end of life, it is care that helps or soothes a person who is dying. The goals are to prevent or relieve suffering as much as possible and to improve quality of life while respecting the dying person's wishes."

Do Not Resuscitate Order (DNR)

As defined by MedlinePlus, a database form the US National Library of Medicine, "A do-not-resuscitate order, or DNR order, is a medical order written by a doctor. It instructs health care providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating. A DNR order is created, or set up, before an emergency occurs. A DNR order allows you to choose whether or not you want CPR in an emergency. It is specific about CPR. It does not have instructions for other treatments, such as pain medicine, other medicines, or nutrition. The doctor writes the order only after talking about it with the patient (if possible), the proxy, or the patient's family."

Hospice

Considered to be the model for quality, compassionate care for people at the end of life when all attempts at cure or remission have been stopped. Hospice and palliative care are related, but not the same. Both involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person's needs and wishes. Increasingly, people are choosing hospice care at the end of life. Hospice can be provided in any setting—home, nursing home, assisted living facility, or inpatient hospital.

Hospice focuses on caring for the patient, as opposed to curing the disease or illness. Palliative care patients may continue to receive attempts at cure or remission, whereas hospice patients in most cases do not.

Although hospice patients do not normally receive treatments intended to prolong life, in multiple end stage diseases in which attempts at cure have been stopped, hospice patients may live longer than non-hospice patients. How could this be?

Many experts believe it is because aggressive treatments late in life do more harm than good. Forgoing those treatments in favor of hospice not only improves symptom control, it may prolong life!

Hospice provides additional support to the person's loved ones, as well. Hospice care can be provided at home, in a hospice or another freestanding facility, or within a hospital.

Irreversible Condition

A condition caused by injury, disease or illness that cannot be reversed or cured, although treatment may control the symptoms and slow the progression of the disease. With or without treatment many of these conditions can become terminal, or fatal, over time. Many serious illnesses, such as neurodegenerative disorders like Parkinson's disease, are considered irreversible when diagnosed, although the patient often can live for an extended period with proper treatment.

Life Sustaining Treatments

Treatments that, based on reasonable medical judgment, sustain the life of a patient and without which the patient will die. The term "Life Sustaining Treatment" does not include drugs used to relieve pain and suffering, the performance of a medical procedure necessary to provide comfort care, or any other medical care provided to alleviate a patient's pain.

In many circumstances, life-sustaining treatments are a definite benefit to the patient and may help the patient live until health can be restored. In other circumstances, these same treatments only prolong dying, often at great physical, emotional, social, spiritual, and financial cost. Medical interventions that sustain the life of seriously ill patients, including those with serious brain injuries, are not considered life support when a patient has been declared brain dead. In that setting, the interventions should be referred to as organ support treatment.

Life-sustaining treatment includes both life-sustaining medications and artificial life support including but not limited to:

Antibiotics
Drugs used to fight infection (pneumonia, for example).

Artificial Nutrition/Hydration (Tube Feeding)
A method of delivering nutrients and fluids to the body when a patient is unable to eat or drink. The most common pathways are a tube put through your nose into your stomach (for short-term use); or a tube put through the skin into your stomach (for long-term use). It works best if you are healthy enough (even with your illness or disability) to benefit from feeding; your illness or disability makes it hard to swallow or take in enough nutrition, or you need tube feeding for a short time to recover from surgery or a sudden illness.

Tube feeding may NOT help you live well if you are older or your body is becoming weak from chronic health problem, you have an illness that can no longer be treated, or your body is failing, in spite of treatment, and death is likely in the near future.

According to Dr. Kendra Belfi, in multiple studies tube feedings have not been shown to prolong life or improve quality of life in advanced dementia such as Alzheimer's disease.

You may have fears about not getting food or water. You may think you will starve or be uncomfortable. This is not true. When food and water are not given, you will die naturally from your chronic illness. You will not feel hungry, and you will receive good care to make you comfortable.

Cardiopulmonary Resuscitation (CPR):

CPR is done for you by someone else. It can include:

- Breathing into your mouth and pressing on your chest.
- Electrical shock and drugs to try to start your heart.
- A tube to help you breathe.

CPR does not help as much as most of us think. CPR works best if you are healthy with no illness, or if it can be given to you within a few minutes of when your heart or lungs stop working. CPR does not work as well if you have chronic health problems, an illness that can no longer be treated, or you are older and weak.

If you are in the hospital, over the age of 65 and get CPR, you have a 22 percent chance of it working and leaving the hospital alive. If you are older, weak, and living in a nursing home it is successful less than 3% of the time.

Intravenous (IV) Line:
A tube placed in a vein that is used to administer fluids, blood or medication

Kidney Dialysis Treatment
The process of cleansing the blood of toxins and removing excess fluid from the body when the kidneys are no longer able to do so.

Ventilator (Breathing Machine)
A ventilator is a machine that supports breathing. It pushes oxygen into your lungs to help you breathe. It is hooked to a tube that goes through your mouth and throat into your trachea (windpipe). You cannot speak or swallow when this tube is in. You will need medicine to help you stay calm. You will need to be in the Intensive Care Unit (ICU) while on a

ventilator. A ventilator will work best if your lung problem can be fixed, or you are using either device for a short time to get better after surgery or a sudden illness. A ventilator will not work as well if your body is shutting down from long-lasting health problem, you have an illness that can no longer be treated, or you are not able to stand the air pressure required to move oxygen in and out of your lungs.

When making decisions about specific forms of life-sustaining treatment, speak to your doctor and gather the facts you need to make sound informed decisions. In particular, understand the benefit as well as the burdens that the treatment will offer you or your loved one. A treatment may be beneficial if it relieves suffering, restores functioning, or enhances the quality of life. The same treatment can be considered burdensome if it causes pain, prolongs the dying process without offering benefit, or detracts from a person's quality of life. When gathering information about specific treatments, understand why the treatment is being offered and how it will benefit your care.

Organ Donation

According to the Cleveland Clinic, "Organ donation is the process of surgically removing an organ or tissue from one person (the organ donor) and placing it into another person (the recipient). Transplantation is necessary because the recipient's organ has failed or has been damaged by disease or injury. Organ transplantation is one of the great advances in modern medicine. Unfortunately, the need for organ donors is much greater than the number of people who actually donate. Every day in the United States 18 people die waiting for an organ and more than 117,000 men, women, and children await life-saving organ transplants."

Palliative Care

An approach to treating serious illness focused on the patient's physical, emotional, social, and spiritual needs. The goal is to achieve the best quality of life possible for the patient by relieving not only physical pain and symptoms like nausea or shortness of breath associated with advance illness, but also emotional, social, and spiritual pain.

Palliative care may be provided by many types of physicians who treat serious illness, but as primary disease advances or symptom burdens increase, it is often advisable to have a specialist in palliative care involved in the patient's treatment and care.

Typically, palliative care is provided by a specially trained team of doctors, nurses, social workers and other specialists who work together with a patient's doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Palliative care may be provided in association with attempts at curative treatment, and in at least some serious illnesses, patients who receive palliative care live longer than those who do not receive it. Palliative care may also at some point replace attempts at cure or remission of illness, and such care is often referred to as "comfort care only." Hospice is the final stage of palliative care.

Terminal Illness/Terminal Condition

In many countries, a condition or illness is considered terminal when death is imminent. In most states of the United States, a terminal condition is an incurable condition caused by injury, disease, or illness that according to reasonable medical judgment will produce death in a short time, even with available life-sustaining treatment.

There is no precise, universally accepted definition of "a short time" in the United States, but in general it is considered to be less than one year in some states, and less than six months in others. The United States federal Medicare hospice care benefit is based upon life expectancy of six months or less.

Withholding or Withdrawing Treatment

Foregoing life-sustaining measures or discontinuing them after they have been used for a certain period of time.

Resources

Baylor Scott & White Health: www.baylorhealth.com/SiteCollectionDocuments/Documents_BHCS/BHCS_Patient%20Info_DocumentsForms/SimpAdvCarePlanGuide_rev10.pdf

Compassion & Choices-Care and Choice at the End of Life: The Good-to-Go Toolkit: www.compassionandchoices.org/wp-content/uploads/2016/02/Good-to-GoToolkit-FINAL-2.1.16.pdf

The Conversation Project: Your Conversation Starter Kit: theconversationproject.org/wp-content/uploads/2015/11/TCP_StarterKit_Final.pdf

My Directives: www.mydirectives.com/en/help/conversation-starters/discussion-guide

The National Hospice and Palliative Care Organization: Caring Info: www.caringinfo.org/i4a/pages/index.cfm?pageid=1

North Texas Respecting Choices: www.northtexasrespectingchoices.com/wp-content/uploads/ntrc_planningguide_8.5x11_fn.pdf

What Matters: Caring Conversations about End of Life: www.jccmanhattan.org/jewish-living/advanced-care-planning

Additional helpful resources:

The Center for Jewish End of Life Care:
www.centerforjewishendoflifecare.org

Five Wishes: agingwithdignity.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2

Life Gift: Organ Donation: www.lifegift.org

Notes

Advance Care Planning Committee of Fort Worth & Tarrant County

For more information, contact:

Cantor Sheri Allen, Chair
817.229.5140
cantorsheri@gmail.com

The Jewish Federation
OF FORT WORTH & TARRANT COUNTY

Beth-El
Congregation

Congregation
Ahavath Sholom

congregation beth shalom

Congregation
Beth Israel
COLLEYVILLE, TEXAS