# Advance Care Planning Guide

ST. CROIX HOSPICE

***“I have a healthcare directive not because I have a serious illness, but because I have a family.”***

-Dr. Ira Byock, author and palliative care physician


# The Value of Planning Ahead

Life is full of twists and turns, and we never know exactly what tomorrow holds. In your final days, will you have a plan in place? Reflecting on our end-of-life wishes doesn't have to be scary. In fact, one of the greatest ways we can honor our life is by having a plan for the future.

Read this guide to learn more about how you can empower yourself and your loved ones through advance care planning.

# What is Advance Care Planning?

Advance care planning involves making important decisions about the medical care you want to receive if you are unable to speak for yourself. In the event that medical professionals and family members need to make decisions on your behalf, advance care directives ensure your wishes are followed.

The advance care planning process includes thinking about your end-of-life wishes, talking with your loved ones and formalizing a plan.

# Who Should Have an Advanced Care Plan?

Advance Care Plans are not just for the elderly and terminally ill. Everyone over the age of 18 should have plans in place. Don’t wait until you are older or until you have a health crisis to make a plan.

# Why Make an Advance Care Plan?

## Studies show that advance care planning:

- Reduces aggressive treatments and hospitalizations.
- Increases the likelihood that you receive end-of-life care in keeping with your wishes.
- Lessens anxiety and stress for family members and loved ones.
- Leads to improved access to palliative and hospice services.

Source: The Pew Trusts, The Case for Advance Care Planning, 2015

# Where Do I Begin?

**Advance care planning has three main components:**

1. Reflecting on your end-of-life wishes.
2. Discussing those wishes with your loved ones and provider(s).
3. Formalizing your wishes through documentation.

It is important to understand that you can always adjust your Advance Care Plan if your wishes change over time. As you move through life, these documents should be reviewed and updated annually.

# Reflecting on Your Plan

Begin your advance care planning by asking yourself questions about how you would want to receive care if you are not able to speak for yourself.

**Things to consider when making your plan:**

- Who would I choose to speak for me if I were unable to speak for myself? (I.e., who would be my Health Care Proxy?)
- What forms of physical, emotional and spiritual comforts are important to me?
- When would I want to stop life-sustaining treatment and begin comfort care?
- What do I want family members to know about my end-of-life wishes?

# Discussing Your Plan

After you have given it some thought, talk with your loved ones about your care preferences for a medical emergency and for the end of life. It’s best to start these conversations when you are in good health, instead of waiting for a crisis. Conversations should include discussions about emergency treatments, comfort care and your personal values. You can also speak with your primary care provider or specialists about specific advance care decisions that may be relevant to your current health.

# Formalizing Your Plan Through Documentation

After reflecting on your wishes and talking with loved ones about your Advance Care Plan, it's time to get your plan in writing. The documents that provide a record of your advance care planning are called advance directives. There are two main advance directive components to complete in order to ensure a formal record of your advance care planning:

1. **Medical Power of Attorney:** allows you to designate a Health Care Proxy (or Agent) who will make medical decisions on your behalf if you are unable to speak for yourself.

2. **Living Will:** outlines your specific medical treatment preferences in the event you cannot communicate your wishes during a medical emergency.

Each U.S. state has its own set of advance directive documents. Because advance directive laws vary from state to state, you might notice that state-specific advance directive forms may be a little different in the way they are titled or structured.

***Visit stcroixhospice.com/advance-care-planning for a link to state-specific advance directive information.***

**REMEMBER:** Always be sure your documents are signed and saved where they're accessible to providers and your loved ones. It is also a good idea for you and your loved ones to keep copies on your cell phone for easy access in an emergency.

# Designating Your Legal Health Care Decision Maker

As you reflect on your Advance Care Plans and prepare your advance directives, you will need to ask yourself an important question: Who do I want making medical decisions on my behalf if I am unable to speak for myself? This person is considered your Health Care Proxy (or Agent*).

When you complete advance directive documentation, you will need to provide this person's information in the Medical Power of Attorney section.

**Choose a Health Care Proxy who:**

- Respects your personal beliefs and values, including your end-of-life preferences.
- Is a trusted family member or friend.
- Can remain focused in emotional situations.
- Is available if an urgent medical decision arises.
- Will advocate and stand up for you.
- Is comfortable asking difficult questions of medical staff—even when they are busy.

*Throughout the rest of this document, we refer to the medical decision maker as a Health Care Proxy.

# Completing Your Living Will

Different than a last will and testament, a “Living Will” contains directives on how you would or would not like to receive medical care while still alive. If you were unable to speak for yourself and needed medical attention, your Living Will would contain a set of instructions on how medical providers should proceed with your care.

**Examples of some medical choices you could include in your Living Will:**

- **Cardiopulmonary resuscitation (CPR):** I do/do not want CPR to restart my heart if it stops beating.
- **Pain medications:** I do/do not want pain medications at end of life to keep me physically comfortable.
- **Feeding tubes:** I do/do not want to be given nutrition and fluids via a feeding tube at the end of life.
- **Ventilators:** I do/do not want help breathing if I am unable to breathe by myself.
- **Comfort care:** I do/do not want comfort care, such as hospice care, to help manage pain and keep me comfortable at the end of life.

The components of a Living Will are included within each state’s set of advance directive forms. As mentioned earlier, you can visit stcroixhospice.com/advance-care-planning for state-specific advance directive information.

# Other Types of Advance Directives

Additional advance directives that may or may not already be included as part of your state's advance directive forms include the following:

- **Do Not Resuscitate (DNR) Order:** DNRs are legally binding medical documents that dictate you do not wish to receive CPR or be resuscitated in the event you stop breathing. A physician would need to provide and sign this document for you, so speak with your primary care provider if you are interested in learning more about having a DNR Order.

- **Do Not Intubate (DNI) Order:** Similar to a DNR, a DNI tells healthcare professionals that you do not want to be intubated, i.e., you do not want a tube inserted into your airway, in the event you need support breathing.

- **Organ and Tissue Donation Form:** These forms authorize the donation of your organs and tissues when you're no longer using them. Organ and tissue donation forms are sometimes built into a state's set of advance directives. If you would like to be an organ and tissue donor but do not have a driver's license indicating you're an organ donor, and you are unable to indicate this preference in your state's advance directive forms, visit organdonor.gov.

- **MOLST, MOST, POLST or POST Forms:** Different states call this form by different names, but they are all similar to a Living Will in that they outline directives for medical care in case you cannot speak for yourself. However, unlike a Living Will, these forms are actual orders entered into a patient's medical chart by a provider. Living Wills can be drafted without a medical provider, but MOLST/MOST/POLST/POST forms involve a discussion with a healthcare professional. These forms can be especially helpful if you are terminally ill or have a recurrent life-threatening illness.

- **MOLST:** Medical Orders for Life Sustaining Treatment

- **MOST:** Medical Orders for Scope of Treatment

- **POLST:** Physicians Orders for Life Sustaining Treatment

- **POST:** Physicians Orders for Scope of Treatment

# Important Things to Remember

- **Sign your advance directives.** Your advance directives are not effective unless you sign them.

- **Make sure your advance directives are accessible.** Make copies for yourself and your loved ones, give them to your primary care provider and let loved ones know where to find them--especially your Health Care Proxy. Save copies on your and your loved ones' cell phones, that way providers can be emailed the info they need at any moment.

- **Primary care providers can save your advance directive information to your electronic medical record (EMR).** However, if you receive care outside of your network, other providers won't have access to your EMR, which makes it especially important to have copies of your advance directive saved in multiple, accessible locations.

- **Update your advance directives as needed.** Once you have signed your advance directives, they do not expire. However, you can and should revise these documents when necessary, as your preferences could change over time.

- **Visit stcroixhospice.com/advance-care-planning for a link to your state's advance directive forms.** If you travel frequently or move between states, you should fill out additional state-specific forms.

# FAQs

### Do I need a lawyer to complete and finalize my advance directives?

A lawyer is not necessary to complete and finalize your advance directives. However, it is common for states to require additional signatures from a notary public or witnesses.

### Where do I keep my advance directives?

You should keep your advance directives in a safe, accessible place. You should also have copies made of your advance directives for your healthcare provider(s), loved ones and especially for your Health Care Proxy. They should all know where to find your documents. It is also wise to share your advance directives with your primary care physicians and loved ones via email so that they have easy access to your documents in the event they're needed. Consider keeping copies on cell phones.

### Is a Living Will the same as a last will and testament?

A Living Will pertains to your medical wishes while still alive but unable to speak for yourself. A last will and testament, however, goes into effect once you are deceased and gives instructions on how you would like your property dispersed.

### How long do my advance directives last?

Your advance directives do not expire, but they should be updated as necessary. Throughout time, your advance care planning preferences may change. Those preferences should be updated in your advance directives. Be sure to redistribute copies of your updated advance directive documents if/when you revise them.

## Is a Health Care Proxy the same as a Power of Attorney?

A Health Care Proxy is not necessarily the same as a Power of Attorney in that a Health Care Proxy only makes decisions on your behalf if you are medically incapacitated. Power of Attorney gives someone additional power and responsibility to manage your affairs beyond medical treatment. There are different types of Power of Attorney, each with different specifications regarding their role. In some advance directive forms, there is a Medical Power of Attorney section where you can name your Health Care Proxy.

**Reminder:** This guide is not a legal document, and we recommend consulting with an expert for more information on how to build an Advance Care Plan that is personalized to your unique needs and wishes.

# The Role of Hospice in End-of-Life Planning

Hospice is not a place; it's a plan. Understanding the benefits of hospice and when to use it is an important part of advance care planning.

Research shows that hospice patients live an average of 29 days longer than terminally ill patients without hospice care. For people with terminal illnesses, starting hospice early can mean an improved quality life through:

- More quality time with family, friends and loved ones.
- Reduced need for invasive procedures.
- Emotional, spiritual and physical support for patients, families and caregivers.
- Relief from stress and anxiety.
- Less likelihood of hospitalization.
- Pain and symptom management.

# Glossary of Terms

**Advance Care Planning:** Premeditated plans for the medical care you want to receive if you are unable to speak for yourself.

**Advance Directives:** Legal documents that formalize your advance care planning and inform your care team and family members of your health care preferences.

**DNR (Do Not Resuscitate) Order:** This order tells your care team not to perform CPR (cardiopulmonary resuscitation) to keep you alive if your heart stops beating.

**DNI (Do Not Intubate) Order:** This order is similar to a DNR and tells your care team you do not want the assistance of a breathing machine.

**Health Care Proxy:** A legally designated decision maker who would speak on your behalf to ensure you receive the health care you would want if you were unable to communicate. Some legal documents may refer to Health Care Proxies as Health Care Agents.

**Living Will:** A Living Will is a document that states the medical treatment you want or do not want if you are unable to speak for yourself.

**Medical Power of Attorney:** This document designates a Health Care Proxy to make medical decisions for you if you are near death or unresponsive.

**MOLST, MOST, POLST and POST Forms:** These documents allow you to give directions to your care team if a medical emergency occurs. They are created for patients in serious advanced illness and must be signed prior to an emergency situation by a doctor or nurse practitioner.

# Resources

- stcroixhospice.com/planning
- caringinfo.org/planning/advance-directives/
- organdonor.gov
- cms.gov/glossary
- nia.nih.gov/health/advance-care-planning-advance-directives-health-care

# About St. Croix Hospice

Originally founded in Minnesota, St. Croix Hospice is named after the St. Croix River. Like life, rivers are not always easy to navigate, and it's good to have a guide to help you along the way. St. Croix Hospice offers experienced and compassionate hospice care to help patients and their families make the most of their time together. We are there when you need us the most.

Visit stcroixhospice.com to access additional resources and to learn more about the benefits of hospice care.