



Advance Care Planning for Hospice Patients: A Guide to Making Informed Decisions

Advance care planning is a crucial part of ensuring that your medical care aligns with your personal values, goals, and preferences, especially when facing a life-limiting illness. It involves making decisions about the kind of care you want to receive in the future, should you become unable to communicate those wishes due to illness or injury. For hospice patients, advance care planning is even more significant, as it helps ensure that end-of-life care is focused on comfort, dignity, and personal choice.

Here's what you need to know about advance care planning for hospice patients:

What is Advance Care Planning?

Advance care planning (ACP) is the process of discussing, documenting, and making decisions about future healthcare based on your values, goals, and preferences. This process includes considering your medical treatment preferences, the type of care you wish to receive if you become unable to speak for yourself and selecting a trusted person to make decisions on your behalf when you're unable to do so.

In the context of hospice care, advance care planning ensures that decisions about your care are aligned with your wishes as you approach the end of life.

Why is Advance Care Planning Important for Hospice Patients?

Hospice care focuses on providing comfort, dignity, and relief from symptoms in the final stages of life. This care is centered on quality of life rather than extending life through curative treatments. Advance care planning is vital because it:

- **Ensures your wishes are honored:** Advance directives (legal documents outlining your healthcare preferences) ensure that your decisions about care are followed, even if you become too ill to express them yourself.
- **Provides clarity for loved ones:** It can relieve family members from the burden of making difficult healthcare decisions at a time of emotional stress.
- **Supports comfort-focused care:** It helps the hospice team understand your goals for care, allowing them to provide treatment that aligns with your values, such as prioritizing pain management over life-sustaining treatments.

Key Elements of Advance Care Planning

Advance care planning typically involves three main components:

1. **Healthcare Proxy or Durable Power of Attorney for Healthcare**



A healthcare proxy is a person you choose to make medical decisions on your behalf if you are unable to communicate them yourself. This person is often referred to as your healthcare agent or surrogate.

- **Choosing a healthcare proxy:** Your healthcare proxy should be someone you trust, such as a spouse, child, or close friend. They need to understand your values and be willing to advocate for your preferences, even in difficult situations.
- **Discuss your wishes:** Have an in-depth conversation with your chosen proxy about your values, treatment preferences, and what kind of care you would want during end-of-life. This will help them make decisions that are consistent with your desires.

2. **Advance Directives (Living Will)**

An advance directive, also known as a living will, is a written document that outlines the types of medical treatment you do or do not want if you are terminally ill or unable to communicate your wishes. For example, you may state your preferences regarding:

- **Life-sustaining treatments:** Whether you want interventions like mechanical ventilation, CPR, or artificial nutrition if your condition becomes critical.
- **Palliative and comfort care:** You may choose to decline aggressive treatments in favor of managing symptoms and ensuring comfort.
- **Organ donation:** You can indicate whether or not you wish to donate your organs or tissues after death.

It's important that you communicate these preferences clearly and review them regularly, as your views may evolve over time.

3. **Do Not Resuscitate (DNR) or Do Not Intubate (DNI) Orders**

A DNR order is a specific advance directive that states you do not want CPR if your heart stops or you stop breathing. A DNI order specifically addresses your preference to avoid being intubated (using a breathing tube).

- **Hospice and DNR/DNI:** Hospice care often includes a DNR/DNI order as part of its focus on comfort care. You and your healthcare team can discuss whether a DNR/DNI is appropriate based on your goals for end-of-life care.

How to Begin Advance Care Planning

1. **Start the Conversation Early**

Advance care planning should ideally begin as soon as possible after a diagnosis of a serious illness. The sooner you start, the more time you have to think about your preferences and discuss them with loved ones and healthcare providers. The conversation



should not be limited to family members; your medical team, including your hospice care provider, can guide you in making informed choices.

2. **Discuss Goals and Values**

Ask yourself what kind of care you want during the end of life. Some questions to consider include:

- What is most important to me in the final stages of life (comfort, pain relief, being surrounded by family, spiritual peace)?
- How do I feel about life-sustaining treatments (e.g., resuscitation, mechanical ventilation)?
- What quality of life would make me feel that my care is meaningful and dignified?

Discuss these questions openly with your family and healthcare proxy so they understand your perspective and can advocate for your choices when necessary.

3. **Involve Your Healthcare Providers**

Your hospice care team can play a key role in helping you clarify your goals and make decisions. They can help you:

- Understand the available treatment options.
- Discuss the benefits and potential burdens of different types of care.
- Clarify the difference between palliative care (focused on symptom management) and curative treatment.

Hospice nurses, doctors, and social workers can provide guidance on end-of-life care and ensure that your choices are documented and respected.

4. **Document Your Wishes**

Once you've made decisions about your care, it's important to document them in the appropriate legal forms:

- Complete your advance directive (living will).
- Appoint a healthcare proxy through a durable power of attorney for healthcare form.
- Ensure that any DNR or DNI orders are included in your medical records.

Keep copies of these documents in a place that is easily accessible, and share them with your healthcare provider, family, and your healthcare proxy. It may also be helpful to carry a wallet card indicating that you have an advance directive in place.



Reviewing and Updating Your Plan

As your health condition changes, it's important to revisit your advance care plan regularly. For example, you may want to reconsider certain decisions if your prognosis changes or if you experience new symptoms. It's also important to have periodic conversations with your healthcare proxy to ensure they are still in agreement with your care preferences.

The Benefits of Advance Care Planning in Hospice Care

1. **Reduced Stress for Family Members:** When your care preferences are clearly documented, your family won't be left to make difficult decisions on your behalf during an emotionally overwhelming time.
2. **Better Care Aligned with Your Wishes:** Advance care planning helps the hospice team focus on care that matches your values and goals, ensuring that you receive comfort-oriented care and avoid unnecessary treatments.
3. **Increased Peace of Mind:** Knowing that your wishes are documented and that your loved ones understand them can bring peace of mind both to you and your family.

Final Thoughts

Advance care planning is an important part of ensuring that your end-of-life care reflects your values and desires. For hospice patients, it helps ensure that the focus remains on comfort, dignity, and quality of life. By having these important conversations early and documenting your wishes, you provide clarity for your family and healthcare providers, allowing them to make informed decisions on your behalf.

Remember that advance care planning is a flexible, ongoing process. It's never too early to start, and it's always a good idea to revisit your plan as circumstances change. Working with your hospice team to document your wishes will help ensure that your care is aligned with your goals during this important time in your life.