

# Advance Healthcare Planning



Navigating the uncertainties of progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) or multiple system atrophy (MSA) can be overwhelming. Understanding your diagnosis and its potential symptoms, treatments and prognosis can influence how you make sense of your future and make decisions regarding your care.

Advance care directives are helpful tools for assisting you in defining and discussing your wishes for medical care. They also offer an opportunity to put in writing the care you want during medical emergencies, when seriously ill or at end-of-life, thereby helping someone to represent your choices when the time comes.

We hope that this resource will offer clarification on advance care directives and considerations to guide you in having open conversations with your support network and documenting your wishes.

Common advance care directives include:

- **Healthcare Power of Attorney**
  - Designates and authorizes a proxy or agent to carry out your healthcare and life-support wishes in the event that you are not able to make or verbalize your own decisions.
  - Names alternate or successor agents to make decisions, should the primary healthcare power of attorney not be able or willing or cannot be reached.
  - The healthcare power of attorney is not the same as a financial power of attorney. You may choose a different person to act as your proxy for healthcare decisions than for financial decisions.
  - Choose a healthcare power of attorney that you trust to carry out your wishes for care. Discuss this decision with them ahead of time to make sure they understand your wishes and are able and willing to perform this role if needed.
  - It is ideal for your primary healthcare power of attorney to reside in the same state as you.
- **Living Will for a Natural Death**
  - Documents a person's wishes about medical interventions when in terminal or very serious medical conditions and the person is unable to communicate, such as a coma or advanced dementia.
  - Can help to guide your healthcare power of attorney on what life and death with dignity means to you under different circumstances.
  - Because of the common word "will," a Living Will is sometimes confused with a Last Will and Testament. A Last Will and Testament communicates directives for division of personal effects and assets, rather than medical wishes.

- **Do Not Resuscitate (DNR) and Do Not Intubate (DNI) orders**
  - If a person has no pulse and is not breathing, these orders instruct medical personnel not to revive your heartbeat or breathing, including by cardiopulmonary resuscitation (CPR), electric shocks (defibrillation), intubation (breathing tubes) and cardiopulmonary medications.
  - In the United States, most DNR orders include DNI; however these are sometimes separate orders or forms. The exact wording on DNR/DNI varies by state.
  - Medical personnel will try to resuscitate someone unless they have evidence that they have chosen to be DNR/DNI. In many cases, they will need to be shown the original medical order.
  - This document is a medical order that must be completed with and by a healthcare provider.
- **Other medically-ordered advance care directives**
  - In the United States, these directives have different names depending on the state where you live. Examples include physician orders for life-sustaining treatment (POLST) and medical orders for scope of treatment (MOST).
  - These directives often include a section on resuscitation but go beyond that into other medical interventions to offer guidance on care in emergency situations or near the end of life.
  - You can choose your preference for level of intervention, from comfort measures only to limited additional interventions to full scope of treatment.
  - You can also choose your preferences for use of antibiotics, intravenous fluids and feeding tubes.
  - Like the DNR, these directives are completed with and by a healthcare provider. The type of practitioners who can sign these orders varies by state and may include a physician, nurse practitioner and physician assistant.

Helpful information (and busting some common myths) about advance care directives:

- **An attorney is not required to complete advance care directives.** In the United States, each state offers a few different forms for Healthcare Power of Attorney and Living Will that are considered legal. You can usually find these forms or templates by searching online, through your hospital system or by asking someone on your healthcare team. An attorney is not required but can be helpful in drafting personalized documents. In some states, advance care directives are legal once they have been signed by the patient while some states require witnesses or notarization. DNR/DNI and other medical orders must be completed with, and signed by, a medical provider to be legal.
- **Be aware that Living Will for a Natural Death and DNR/DNI orders are different forms and are often used in different circumstances.** It is common for people who have completed their Living Will to think that it covers resuscitation. DNR/DNI is typically used in emergency situations, when a person's heart and breathing stops. A Living Will acts as a more general guide for healthcare powers of attorney on a person's care wishes or may be used when making decisions about using or ceasing medical interventions.
- **Seek education on your diagnosis and on medical interventions prior to completing advance care directives.** Often, medical interventions, such as resuscitation, look different in real life than how we are mostly familiar with them, which is through media portrayal. Understanding what medical and life-sustaining interventions would look like for you, depending on factors like your age and health status, can help you make decisions around your care. Additionally, your understanding of your diagnosis, symptoms, treatment options and prognosis are also important factors in defining your wishes and making decisions around your care. While not an easy conversation, it can be helpful to speak with your family physician, neurologist or other healthcare providers about these directives.

- **Inform your healthcare team that you have completed advance care directives.** You may have worked with someone on your healthcare team to complete your advance care directives, or they may have been placed in your medical records during a hospitalization. However, many healthcare providers are not alerted to this fact and may not be aware that you have completed advance care directives. Discuss your wishes with your healthcare team and inform providers during hospitalizations or clinic visits if they do not ask. You can provide them with a copy and ask them to confirm that it has been included in your electronic medical records. Also inform professional caregivers, staff of long-term care facilities and hospice teams of your wishes and the location of your directives (or copies of them).

#### Answers to frequently asked questions:

- **When is the right time to complete advance care directives?**

It is never too early to discuss care wishes and decisions with your family and healthcare team, as this helps to relieve the burden of not knowing what you may have wanted. Getting everyone on the same page and having open and safe conversations, especially when not in a time of crisis, can offer comfort and peace of mind for you, your family and your healthcare team.

It is helpful to complete your Healthcare Power of Attorney and Living Will as early as possible. For DNR/DNI and other medically-ordered directives (e.g., POLST), most people who complete them do so when they are at higher risk of hospitalization and complications or when they have more complex medical needs, including chronic and progressive health conditions. However, you can complete DNR/DNI and other medically-ordered directives at any time, especially if you have very strong preferences about these interventions.

- **Can advance care directives be changed or undone?**

Yes! While they are legal documents, they do not have to be set in stone and can evolve as your wishes for care may change over time, which often happens as we age, reflect on experiences and live with different and changing health conditions.

It is helpful to review your advance care directives periodically to confirm that they still reflect your current wishes. You can end or update an advance care directive at any time by informing your healthcare team and healthcare power of attorney and writing “void” on the previously created documents, and/or by completing an updated document.

Additionally, many U.S. states will recognize advance care directives created in other states, but they may not be considered legal. If you move to a new country or state, it is important to update your advance care documents to those legally recognized and valid in your new location.

- **Where should I keep these documents?**

Many people seem to think that copies of advance care directives should be kept in a safe deposit box with other important papers; however, a safe deposit box can be difficult to access at times. Keep a copy of your Healthcare Power of Attorney and Living Will at home in a safe and easily accessible location. Also give a copy to your Healthcare Power of Attorney and one or two other close family members. It is helpful to have extra copies on hand as well, in addition to making sure it is put on file with your healthcare providers in your electronic medical record. Some U.S. states maintain registries that allow quick access by proxies and healthcare providers.

For DNR/DNI and other medically-ordered advance care directives (e.g., POLST), keep these in a prominent location that would be visible to medical personnel, such as next to the bed or hanging on the front door or refrigerator. Bring the original document with you in the event of a hospitalization or stay in a rehabilitation or long-term care facility.

- **Are there other resources to learn about advance care directives?**

Five Wishes is an advance care directive that is legal in most (but not all) 50 U.S. states. They include Healthcare Power of Attorney and Living Will, as well as questions around specific wishes at end of life, such as the surrounding environment of your death, preferences for memorial services and how you wish to be remembered. Visit [www.fivewishes.org](http://www.fivewishes.org) to learn more.

The National Hospice and Palliative Care Organization offers resources on advance directives, palliative care and more to further clarify these important topics and guide conversations for you and your family. Visit [www.caringinfo.org](http://www.caringinfo.org) for more information.

Additionally, Values History Forms are tools that can help you to make healthcare decisions in line with your values. Values History Forms may cover your goals for the future, understanding of your health, fears, preferences for end of life, definition of pain and suffering, beliefs around dignity and quality of life, and important messages you wish to share. You can find different versions of Values History Forms online.



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