# Advance Care Planning

Advance care planning involves preparing for future decisions about medical care. It allows you to reflect on what matters most to you, have open discussions with the people you trust, and document your preferences so they can be honored if your ability to communicate changes.

### Advance care planning can help you:

- Clarify what quality of life means to you
- Identify the kind of medical care that aligns with your values
- Reduce uncertainty for your care partner and family

## WHEN TO BEGIN

Starting the planning process early can be incredibly beneficial. Early planning gives you the time and space to reflect and converse without added pressure.

### You might consider beginning:

- Shortly after diagnosis
- During a routine neurology appointment
- When you feel ready to talk about your future planning

It is important to remember that you do not need to have all the answers right away. The key step is to start the conversation. If you are unsure how to start, conversation based tools can offer guidance and prompts to help facilitate discussion.

## REFLECTING ON WHAT MATTERS MOST

Before completing the documents, take time to reflect on your values.

### Consider:

- How do I define a good quality of life?
- What types of medical care align with my values?
- Who do I trust to help make decisions if necessary?

In MSA, as the disease progresses, some decisions that may arise include whether to pursue feeding tube placement, breathing support, speech loss, or how you would like to be cared for during hospitalizations. Thinking about these scenarios ahead of time can help ensure your care aligns with your values.

## STARTING THE CONVERSATION

Talking about future care can feel difficult, even when you know it matters. There is no perfect moment or perfect way to begin.

You may open by sharing that you have been thinking about your future care and want the people you trust to understand your wishes. Some people find it easier to start with a question rather than a statement, such as "Can we talk about what I would want as my symptoms progress or when things get harder?"

### Consider having these conversations with:

- Your spouse or partner
- Your adult children
- A trusted friend
- Your neurologist or healthcare provider

It can help to have multiple conversations over time, rather than trying to cover everything at once. If you are unsure how to begin, The Conversation Project offers free starter guides designed to help people open this kind of dialogue.

Your care partner may also have feelings about these conversations. Making space for them to share what they are carrying can strengthen the process for both of you.

## CHOOSING A HEALTHCARE DECISION MAKER

You can legally name someone to make medical decisions for you. This person may be called:

- Durable power of attorney for healthcare
- Healthcare proxy
- Healthcare agent

When selecting a healthcare decision-maker, consider choosing someone who:

- Understands your values
- Communicates clearly with healthcare providers
- Stays calm in difficult situations
- Is willing to advocate for your wishes

You continue making your own healthcare decisions as long as you are able. The document naming your healthcare agent becomes active only if you become incapacitated or unable to communicate.  You also have the option to name an alternate decision maker.

## PUTTING YOUR WISHES IN WRITING

After you have taken time to reflect and have discussions about your healthcare preferences, the next step is to document your wishes. These documents make your preferences clear.

**Advance Directive:** Is a legal document that outlines your healthcare wishes if you are unable to make decisions for yourself. It typically includes both a living will and a durable power of attorney for healthcare.

**Living Will:** Is a written document that explains the types of medical care you would or would not want in serious health situations. It provides guidance about life-prolonging treatments and other interventions. Its purpose is to communicate your values clearly so your family and healthcare team understand your direction.

**POLST (Physician Orders for Life-Sustaining Treatment):** is a written medical order that requires signatures from either the patient or their legally recognized healthcare agent and by a healthcare provider, such as a physician, nurse practitioner, or physician assistant. This document details your preferences for life-sustaining treatments, including your wishes regarding CPR, intubation, and feeding tubes. Unlike an advance directive, it is followed by healthcare providers, including emergency personnel. This document may be referred to by different names depending on the state, such as MOLST, POST, MOST, and LST.

**Do Not Resuscitate (DNR) Order:** is a medical order that indicates that if your heart stops or you stop breathing, healthcare providers will not perform CPR. This order specifically applies to resuscitation efforts and does not mean that other treatments or comfort care will be stopped. The order is signed by a healthcare provider, based on the patient's wishes or the decisions of their legally recognized healthcare agent.

**Advance directive forms are available through:**

- Your state department of health
- Local hospital systems
- CaringInfo: A program of the National Alliance for Care at Home

*Most forms are free. Some states require witnesses or notarization.*

## STORING AND SHARING YOUR DOCUMENTS

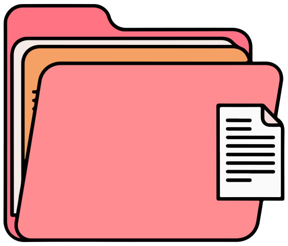
After completing your documents, ensure that the right people have copies and that they are easy to find.

- Provide copies to your healthcare agent and healthcare provider.
- Store documents digitally so your healthcare agent can access them quickly.

Consider creating an emergency folder to store all your important materials and keep them easily accessible. In case of an emergency or if EMS is called and you are unable to communicate effectively, having this folder readily available ensures that the people caring for you have the necessary information.

**Your emergency folder may include:**

- Living will
- Advance directive
- POLST form
- Diagnosis
- Current medications
- Allergies
- *Contact information for your healthcare agent and provider*



## PALLIATIVE CARE AND HOSPICE

**Palliative care** aims to improve quality of life and provide symptom relief. It can begin at any point after an MSA diagnosis and can be offered alongside other treatments you are already receiving. Its goal is to improve quality of life, addressing not just physical needs, but also emotional and spiritual ones.

If you are interested in palliative care, you do not need to wait to be offered it. You can ask your healthcare provider for a referral any time. Palliative care teams often include doctors, nurses, social workers, and chaplains who work together to support both the patients and their families.

### Some of the ways palliative care can help include:

- Managing pain and other physical symptoms
- Supporting emotional and psychological well-being
- Helping you and your family communicate with your healthcare team
- Assisting with difficult decisions about your care

Palliative care and hospice are not separate unrelated options. They are part of a continuum of care, and for many people with MSA, one naturally transitions onto the other over time.

**Hospice care** is a type of care designed for people nearing the end of life. It is typically introduced when a healthcare provider determines that a person has six months or less to live. It is often provided at home and includes support for both patients and their families. As MSA progresses, there may come a point when the goal shifts entirely to comfort. Hospice care supports you through that time.

The hospice team often includes nurses, doctors, social workers, chaplains, home health aides, and volunteers who work together to provide comfort and support. Hospice teams may also provide respite care, giving your care partner time to rest while you continue to receive attentive, compassionate support.

### A few things that are helpful to know:

- Hospice is not giving up. It is shifting the focus to maximizing quality of life, comfort, and dignity.
- Choosing hospice does not mean all care stops. It means goals of care change.

Understanding these options early on can help you recognize the types of support available and what might feel right.

## FINANCIAL AND PRACTICAL PLANNING

Advance care planning is essential for ensuring your wishes are respected. Key components include:

**Review Beneficiary Designations:** Regularly check the beneficiaries on your financial accounts, insurance policies, and retirement funds to ensure they reflect your current wishes.

**Long-Term Care Planning:** Think about what future care might look like for you, whether that is support at home, assisted living, or another arrangement. Understanding the options and their costs early gives you more time to plan thoughtfully.

**Brain Donation:** plays an important role in advancing the understanding of MSA. Because MSA can only be definitively confirmed by examining brain tissue after death, donation supports research aimed at improving diagnosis and expanding scientific knowledge. If you are considering this, it is important to begin the conversation early.

**Funeral or Memorial Preferences:** Document your preferences for funeral arrangements, including burial or cremation and any specific cultural practices you wish to follow.

Addressing these areas offers clarity for your family during difficult times.

## WHEN TO REVISIT YOUR ADVANCE CARE PLAN

Completing your advance directives is not a one-time event. Your health, relationship, and wishes may change over time. It is important to revisit your plan regularly to make sure it still reflects where you are.

### Considering reviewing documents:

- Your MSA symptoms progress
- You are hospitalized
- You change your healthcare decision maker
- You feel your values or wishes have shifted
- It has been a year or more since you last reviewed your documents

When you make updates, share the revised documents with your healthcare provider, healthcare agent, and anyone else who has a copy

# Advance Care Planning

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Leading the Charge to Cure Multiple System Atrophy

## MY ADVANCE CARE PLANNING CHECKLIST

### Next Steps

- ☐ Reflect on your values and what matters to you
- ☐ Choose a healthcare decision maker
- ☐ Have a conversation with someone you trust
- ☐ Complete an advance directive (which includes a living will and health care power of attorney)
- ☐ Talk to your provider about completing a POLST to reflect your current care wishes

### After Completing Your Documents

- ☐ Share your documents with your healthcare provider
- ☐ Keep a copy of your documents somewhere accessible at home

### Additional Planning Considerations

- ☐ Review beneficiary designations
- ☐ Research long-term care options
- ☐ Document funeral and memorial preferences

Visit **missionmsa.org** or scan the QR code to explore more end-of-life planning resources.

## ADDITIONAL EXTERNAL RESOURCES:

### CaringInfo is A program of the National Alliance for Care at Home

*Provides free state-specific advance directives and instructions.*

**Click Here to Learn More**

### The Conversation Project

*Provides free guides helping people share their wishes for care through the end of life.*

**Click Here to Learn More**

### Five Wishes

*Advance care planning document and advance directive tool. Check whether it is legally recognized in your state.*

**Click Here to Learn More**

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