



# **Your Essential MSA Guidebook**

MISSION **MSA**<sup>®</sup>

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# What is MSA?

Multiple System Atrophy (MSA) is a rare and progressive neurological disorder that can cause a multitude of symptoms in any combination, including impairments to balance, difficulty with movement, poor coordination, bladder dysfunction, sleep disturbances, and poor blood pressure control.



## Types of MSA

Symptoms vary between those with MSA-P (Parkinsonian) and MSA-C (Cerebellar).

### PARKINSONIAN

MSA-P is the more common type of multiple system atrophy. The most common symptoms seen with MSA-P are those that are like Parkinson's disease. These symptoms may include slowness or difficulty initiating movement, increased falls due to walking problems associated with shuffling of gait, tremor, rigidity or muscle stiffness, slurred speech, voice changes, drooling, difficulty swallowing, and lack of facial expression.

In the early stages, MSA-P may respond to medications used for Parkinson's disease; however, MSA-P progresses more rapidly than Parkinson's and eventually, most patients no longer respond to those medications.

#### Other common symptoms may include:

- Problems with balance and posture
- Sleep disturbances
- Writing becoming small and spidery
- Difficulty turning in bed

### CEREBELLAR

MSA-C presents with symptoms that affect the part of the brain known as the cerebellum, which coordinates and regulates muscular activity. Due to the cerebellum's role in synchronizing motor movements, people with MSA-C often have difficulty with coordination when it comes to walking, hand movements, speech, and eye movements.

#### Common symptoms include:

- Dropping things
- Unable to balance without support
- Finding it difficult to fasten buttons
- Difficulty writing
- Feeling unsteady or clumsy in crowds
- Slurred speech

## How common is MSA and who gets it?

MSA is a rare disease, which makes diagnosis often difficult and time-consuming. It can take multiple visits to a neurologist or other specialists to get a complete diagnosis.

The large majority of MSA cases are sporadic, meaning they occur at random. MSA affects approximately 5 out of 100,000 people, including people from all racial backgrounds.

Currently, it is believed that there is little to no genetic evidence or proven environmental factors that cause MSA. There has not been a strong genetic link found for MSA, and therefore it is not thought to be passed down to children. Typically, patients show symptoms between the ages of 40 and 60, and it has not been found in patients under 30.

## What parts of the brain does MSA affect?

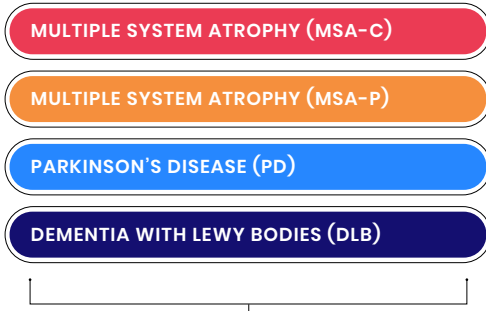
MSA stands for multiple (more than one) system (brain structures and nervous systems) atrophy (brain cell shrinkage and loss). This means that the cells in the brain that control body functions are damaged, typically the basal ganglia, cerebellum, and brain stem. Nerve cells in the affected areas of the brain shrink (atrophy), which can sometimes be seen on an MRI. This is caused by abnormal misfolding and accumulation of the protein alpha-synuclein, and this occurs in the parts of the brain that affect movement and balance, which leads to the damage of these areas and the resulting lack of dopamine, which causes the onset of symptoms.

## What Diseases are Similar to MSA?

**MSA falls into a family of diseases called “synucleinopathies”.**

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Along with displaying similar symptoms, a distinguishing feature of each of these diseases is the buildup of a protein called alpha-synuclein in brain cells, which gives them their synucleinopathy name. The synucleinopathies include MSA, Parkinson’s disease (PD), and Dementia with Lewy Bodies (DLB). In MSA, alpha-synuclein accumulates in specialized cells called oligodendrocytes, which mainly support the function of the brain and spinal cord.



## How is MSA diagnosed?

A neurologist typically diagnoses MSA. Many neurological conditions look similar to MSA in the early stages, so other conditions must be ruled out before MSA is diagnosed.

**Common symptoms that can add up to a diagnosis of MSA include:**

- Lightheadedness, dizziness, or passing out
- Sleep apnea or snoring, dream reenactment
- Subtle changes to speech or voice
- Erectile dysfunction in men/sexual dysfunction in women
- Urinary incontinence or other bladder issues
- Increased falls
- Cold extremities
- Difficulty speaking and swallowing
- Symptoms of Parkinson's with faster progression

Evaluation may be an ongoing process as symptoms progress and change. It is important to provide the doctor with the most accurate and complete symptom and health history information to ensure the best and most accurate diagnostic care.

### What tests will doctors run?

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After clinical evaluations, your doctor will likely order supplemental tests that can assist them in making a diagnosis. An MRI can be used to detect brain changes, skin biopsies can confirm presence of synuclein accumulation, and blood tests can rule out other diagnoses.



# Stages and Symptoms

MSA presents with a diverse range of symptoms, and while there are two different types of MSA, many symptoms are commonly seen in both types.



# Stages and Symptoms of MSA

**Multiple system atrophy (MSA) has stages, each with varying symptoms across patients.**

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## EARLY SIGNS/SYMPTOMS

**Common symptoms that can add up to a diagnosis of MSA include:**

- Lightheadedness, dizziness, or passing out
- Sleep apnea or snoring, dream reenactment
- Subtle changes to speech or voice
- Erectile dysfunction in men/sexual dysfunction in women
- Urinary incontinence or other bladder issues
- Increased falls
- Cold extremities
- Difficulty speaking and swallowing
- Symptoms of Parkinson's with faster progression
- Poor response to Parkinson's medications

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- **Parkinson's Symptoms**

In the early stages of MSA, some patients may find that they are displaying classic symptoms of Parkinson's disease. These symptoms may include a tremor, muscle rigidity or stiffness, and slowness when moving. Often, these symptoms can cause trouble walking, causing a patient to drag or shuffle their feet, or even freeze and feel like their feet are stuck to the ground. Other symptoms may be small and spidery handwriting (micrographia) or slower, quieter, and/or slurred speech.

- **Cerebellar Symptoms**

Patients with cerebellar symptoms struggle primarily with coordination and movement. These symptoms may include feeling clumsy when walking or talking, feeling unbalanced or unsteady, or feeling uncoordinated when trying to complete intricate tasks like fastening buttons.

- **Autonomic Symptoms**

Dysautonomia, which impairs the autonomic nervous system, is a hallmark of MSA. Resulting in issues with blood pressure regulation, heart rate, breathing, and digestion, dysautonomia can lead to problems such as dizziness, fainting when transitioning from lying down to standing (neurogenic orthostatic hypotension), or after eating a meal high in sugar or carbs (postprandial hypotension). Sometimes, patients have high blood pressure while lying down (supine hypertension).

- **Dysphagia**

Dysphagia, or difficulties swallowing, can lead to problems when eating and drinking, increasing the risk of choking and aspiration pneumonia. As MSA progresses, the weakening of the muscles involved in swallowing can make mealtime a challenging and potentially dangerous experience. Managing dysphagia in MSA often requires a multidisciplinary approach, involving speech therapists and dietary modifications, to ensure safe and comfortable eating and drinking for individuals living with this condition.



- **Sleeping Difficulties**

Sleep disturbances are a prevalent and challenging aspect of the disease. An early symptom of MSA is REM Sleep Behavior Disorder (RBD) which causes an individual to act out their dreams, often leading to shouting or thrashing movements while the patient is completely asleep and unaware of their actions. Individuals with MSA also often grapple with irregular breathing at night, which can lead to conditions like sleep apnea, snoring, stridor, and excessive daytime sleepiness. These disturbances not only disrupt the quality of sleep but also contribute to feelings of fatigue and lethargy during the day, further impacting the overall well-being of those affected by the condition.

- **Cognitive Impairment**

As many as 75% of MSA patients may grapple with various cognitive issues, including difficulties with memory, attention, problem-solving, and emotional control. This cognitive decline often necessitates additional time and effort to concentrate on tasks, as fatigue, another common symptom in MSA, can further impact cognitive abilities. Emotional well-being can also be affected, with high rates of depression, anxiety, panic attacks, and even thoughts of suicide observed among patients. While dementia is considered rare in MSA, it may still affect 12 to 18% of individuals, emphasizing the need for comprehensive care and support in managing the cognitive aspects of this complex condition.

- **Urinary Symptoms**

Bladder control is often an early symptom of MSA, with up to 96% of individuals experiencing urinary symptoms. These symptoms include urinary urgency, frequency, incontinence, and/or leakage. Often, individuals don't expect that their urinary symptoms may have an underlying concern, and their urinary symptoms may progress to a urinary tract infection. Diagnosing and managing urinary issues often requires a multidisciplinary approach, typically involving a urologist, who may perform tests to determine the best course of treatment.

- **Additional Symptoms**

Patients often experience additional challenges including erectile dysfunction and constipation.



## END OF LIFE PLANNING

**At some point in your MSA journey, you will need help with your everyday needs. Whether it is a loved one who can serve as a care partner, or hiring a healthcare professional, it is vital to have a care team lined up to assist you and/or your family.**

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MSA is a terminal disease with an average patient survival of 6 to 10 years after the onset of symptoms. Patients and families should begin to have conversations and make decisions regarding palliative care, advanced directives, finances, hospice care, and the possibility of brain donation, if so desired.

**Palliative care** can help maintain quality of life and relieve pain. It would be helpful to become familiar with different agencies in your area early on, so that you can make an informed decision. Healthcare professionals such as social workers can help provide information or where to find it.

**Hospice services** are available for end-of-life care, typically when a patient is expected to survive less than six months. Once a patient is enrolled in a hospice program, the agency will cover anything related to the terminal illness, including medicine, medical equipment, symptom management, home health aides, and chaplain services. Many hospice agencies work with Medicare and private insurance. Social workers can also provide information and support when deciding on hospice programs.



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# Treatment and Management

Due to the rare nature of this disease and the complexity of its symptoms, many MSA patients see a multitude of providers before receiving their diagnosis. It is imperative that a patient's care team provides timely and informative medical care from their multi-disciplinary team to MSA patients and their care partners when treating and managing symptoms.



## Care Team

### It takes a variety of specialists to develop the best treatment plan.

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You will need the support of multiple doctors/therapists who will make up your care team.

Here are potential members of your care team and what they may recommend or help you with, but your exact needs will vary.



**PHYSICAL THERAPISTS**

Physical therapists can help with our movement. Your PT can give you specific exercises that may help prevent falls and maintain mobility.



**OCCUPATIONAL THERAPISTS**

Occupational therapists can help to provide advice and equipment to help you get around safely, including where you can install equipment to help you at home.



**UROLOGISTS AND CONTINENCE SPECIALISTS**

Urologists and continence specialists can help recommend treatment for bladder issues, such as not fully being able to empty your bladder; catheterization can help.

Urologists may also help advise on issues of sexual dysfunction. Men often take medication for this issue, but these medications can worsen blood pressure control, which can be bad for those with MSA.



## SPEECH PATHOLOGISTS

Speech Pathologists can assess your swallow to prevent food from entering your lungs while coughing.



## DIETICIANS

Dieticians can help advise you on a balanced diet to help alleviate some symptoms, prevent choking, and avoid constipation.



## MSA CENTERS OF EXCELLENCE

MSA Centers of Excellence are an all-encompassing resource, as these Centers provide the necessary expertise from a range of providers, including those listed above to ensure those impacted by MSA receive a comprehensive, gold-standard, continuum of care.

- **Movement Disorders Neurologist or Advanced Practice Provider (NP/PA)** will manage the majority of your MSA related care and provide referrals to any other multi-disciplinary team members.
- **Therapists or counselors** can assist you in coping with your diagnosis, and you may find it beneficial to engage with a support group, whether virtually or in person, to connect with others facing similar challenges.
- **Social Workers** can also assist in finding support for you or your family. This may be through a support group, helping with documents for disability or insurance, or helping you navigate end of life planning.

## How should I plan for the future?

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At some point in your MSA journey, you will need help with your everyday needs. Whether that is a loved one who can serve as a care partner, or hiring a healthcare professional, it is vital to have a care team lined up to assist you and/or your family.

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## What legal documents should I fill out?

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It's important to put together an advanced directive, which includes a living will and/or the designation of a Power of Attorney (POA) for healthcare. These documents allow for a patient to decide on their treatment options, such as if they want to be placed on a ventilator, receive CPR if their heart stops, or have a DNR (Do Not Resuscitate) order.

A Power of Attorney (POA) for healthcare allows a friend or family member to make medical decisions if the patient is unable to do so. If you designate a POA, ensure they understand your wishes explicitly. A POA for healthcare is separate from a POA for finances, who can only make financial decisions on the patient's behalf. Make sure to complete both if you wish to designate these responsibilities.

## Am I entitled to Social Security Disability Benefits?

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- Under current federal law, individuals are entitled to Social Security Disability Benefits (SSDI) if:
  - they become disabled due to a medical condition that is expected to last at least one year or result in death.
  - meet certain work history requirements (such as paying Social Security taxes on their earnings.)
- Multiple System Atrophy is on the Compassionate Allowances list, which streamlines the SSDI application process and reduces the standard waiting time for a decision, which may take months.



# Research and Clinical Trials

Under the guidance of expert MSA researchers and clinicians, Mission MSA funds promising research that is directly applicable to identifying:

- A clear cause of MSA
- Improved methods leading to an earlier and more accurate diagnosis
- Better treatments to alleviate MSA symptoms and improve quality of life
- Interventions that slow, halt or reverse the progression of MSA
- A cure for MSA

## What can I do to help research?

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There are increasing opportunities outside of Mission MSA to be recruited as a volunteer in research trials. This can involve completing questionnaires, undergoing scans, collecting blood samples, or participating in drug trials. Due to the small numbers of people with MSA at any one institution, some trials are organized using several sites across the country.

## Should I donate my body to science?

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You may wish to donate your brain to MSA research once you pass away, as this research is valuable to help find a more direct and accurate path to early diagnosis, develop potential treatments, and ultimately a cure. Due to the rare nature of MSA, a brain autopsy is currently the only way to fully confirm the diagnosis.

Brain donation requires a specific protocol for the preservation of the brain until it is harvested. This is a detailed process that must be done within 24 to 48 hours after death. Because timing is critical, arrangements for brain donation and harvest should be in place before the patient is near death.

Our partner organization, The Brain Support Network can help families make plans for brain donation by identifying a lab to do the brain autopsy and finding a pathologist or other qualified individual to do the retrieval.



## Join the Community

Mission MSA exists to provide support, information, and hope for affected persons and their families, fund research, and educate healthcare professionals. Through Mission MSA, you can connect with other MSA patients and care partners through our online or in-person support groups.

If you want to support Mission MSA, you can directly make a tax-deductible donation or start an in-person or online fundraiser to raise additional money and awareness. Your employer may also have a gift-matching program, or you can plan a long-term gift such as naming Mission MSA in your will or as a retirement fund beneficiary.

You can also volunteer with Mission MSA in many ways, including fundraising, advocacy, joining the Board of Directors, contributing to our blog, helping to run support groups, or creating educational content.

Mission MSA is committed to advocating and advancing key legislative issues that affect the multiple system atrophy community. By utilizing our unique position as the voice of the MSA patient, care partner, and researcher, our goals are to inform, influence, and positively impact legislation that advances our mission and vision. We focus on eliminating barriers to Medicare access and federal benefits, provide support for care partners, provide funding for MSA research, and help improve access to care. We hope that you will join us in advocating and raising awareness within your individual networks as well.



**MSA CONNECT**

An online community for those affected by MSA

## Common Terms

Here are a few common terms used in this guide and in the MSA community for your reference:

### Symptoms

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**Akinesia** Inability to move (“freezing”) or difficulty in beginning or maintaining a body motion

**Ataxia** A mobility-impairment condition marked by loss of balance and decreased coordination

**Bradykinesia** The slowing down and loss of spontaneous and voluntary movement

**Cogwheel Rigidity** A type of rigidity in which a muscle responds with cogwheel-like jerks when the muscle is stretched or the limb is bent.

**Dysarthria** Slurred or otherwise impaired speech

**Dysequilibrium** Unsteadiness or balance problems

**Dyskinesias** Involuntary, uncontrollable, and often excessive movement. These movements can be lurching, dance-like or jerky, and are distinct from the rhythmic tremor commonly associated with Parkinson’s disease. A common side effect of many drugs used to treat Parkinson’s disease.

**Dysphagia** Difficulty in swallowing

**Dystonia** Abnormal and awkward posture or sustained movements of a hand, foot, or other part of the body; may be accompanied by rigidity and twisting

**Festination** A quickening of steps and shuffling after starting to walk

## Symptoms Continued

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**Freezing** Abrupt and temporary inability of a patient to move their feet that frequently occurs at a boundary such as a door frame leading to another room

**Hypomimia** Immobile, expressionless face with reduced blinking

**Micrographia** Small, cramped handwriting that is a symptom for many Parkinson's patients

**Orthostatic hypotension** Sudden drop in blood pressure (>20 mm Hg systolic) upon standing and accompanied by symptoms such as dizziness, fatigue, and syncope.

**Pill-rolling** One of the characteristic slower tremors in the fingers of Parkinson's patients; the alternating movements of the thumb and forefinger give the appearance of rolling a small object between the fingers

**Rigidity** Abnormal stiffness in a limb or other body part. It is most apparent when an examiner moves a patient's limb — as in cogwheeling.

**Tremor** Unwanted rhythmic movements (may be fast or slow) that may affect the hands, head, voice or other body parts.



## Medical Terminology

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**Agonist** A drug that imitates a neurotransmitter. Dopamine agonists are drugs that imitate the actions of dopamine.

**Anticholinergic** A drug that blocks the action of acetylcholine, a neurotransmitter in the brain. Anticholinergic drugs are often effective in reducing the tremor of Parkinson's disease.

**Monoamine oxidase inhibitors (MAO)** Drugs that enhance the effect of dopamine by preventing enzymes from breaking them down

**Movement disorders** Refers to several conditions, many of them neurodegenerative, that prevent normal movement. Some are characterized by either lack of movement (bradykinesia, hypokinesia, etc.) or excessive movement (chorea, athetosis, dystonia, tremor). Besides Parkinson's, other conditions often defined as movement disorders include essential tremor, multiple system atrophy, progressive supranuclear palsy, Huntington's disease, Tourette's syndrome, and cerebral palsy.

**Neurodegenerative** Refers to conditions such as Parkinson's that are characterized by the loss of cells in the central nervous system

**On-Off Phenomenon** Sudden loss of activity of levodopa lasting minutes to hours after a brief period of effectiveness. The term also sometimes refers to a cyclical response to medication where the patient can function adequately at times but is too stiff and immobile to function at other times.

**Parkinsonism** Generic term referring to slowness and mobility problems that look like Parkinson's disease. Several conditions, such as multiple system atrophy and progressive supranuclear palsy, and a number of medications produce this appearance.

**Trigger Event** An external or environmental factor such as head trauma, exposure to a toxin, or stress that contributes to the development of a condition or disease.

**Wearing Off** Loss of effectiveness of Parkinson's medications between doses. If the effectiveness of a medication does not last until the next dose is due, it "wears off".

## Anatomy

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**Basal ganglia** Large clusters of neurons deep within the brain that are responsible for voluntary movements such as walking and movement coordination. Includes the striatum, the subthalamic nucleus, and the substantia nigra

**Globus Pallidus** A structure (group of nerve cells) deep in the brain affecting movement, balance, and walking.

**Striatum** Also known as the corpus striatum, it is the largest component of the basal ganglia in the brain and controls movement, balance, and walking

**Substantia Nigra** Literally means “black substance.” A part of the basal ganglia, located in the midbrain, that is rich in dopamine-producing nerve cells and the black pigment neuromelanin (hence its name). In Parkinson’s, the loss of nerve cells from this region leads to a dopamine deficit and subsequently to Parkinson’s symptoms.

**Subthalamic Nucleus (STN)** A nerve center near the substantia nigra. The STN may be targeted for deep brain stimulation (DBS) to reduce Parkinson’s symptoms

**Thalamus** A mass of gray matter (nerve cells) located deep in the brain that is responsible for motor control and serves as a relay center for sensory signals.

## Testing

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**CT (CAT) scan** Computed tomography, a technique that uses a series of X-rays to create image “slices” of the body from different orientations to create a two-dimensional image of the body. The term CAT scan (computed axial tomography) refers to a specific orientation of images.

**MRI (Magnetic Resonance Imaging)** Three-dimensional images of the brain obtained in a scanner using a powerful magnet

**PET scan** An acronym for “positron emission tomography,” an imaging technique used to monitor and produce pictures of metabolic or biochemical activity in the brain

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