# **Stages of MSA**



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

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

#### 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

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.



#### LIVING WITH MSA



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.

#### 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.

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.

