

This document has been prepared to help you become more informed about Multiple System Atrophy. It is designed to answer questions about the condition and includes suggestions on how to manage it.

*Terminology

MSA includes conditions that were previously known individually as Shy-Drager syndrome, striatonigral degeneration and sporadic olivopontocerebellar atrophy. Researchers have learned that there is a common underlying cause in all three disorders, so they are now referred to as MSA.

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Multiple System Atrophy falls into the category of Atypical Parkinsonism, or Parkinson plus syndrome, a group of diseases linked to a lack of dopamine in the brain. Dopamine controls movement. While Parkinson's is the most common Parkinsonism, approximately 20 percent¹ of people will be diagnosed with another Parkinson's-like condition.

What is Multiple System Atrophy?

Multiple System Atrophy (MSA)* is a progressive brain disorder caused by loss of nerve cells in specific areas of the brain. This loss causes problems with movement, balance and autonomic functions of the body. (Autonomic functions are body functions that occur automatically, such as bladder control.)

The term MSA stands for:

Multiple — many

System — brain structures that control different functions

Atrophy — cell shrinkage or damage

Who gets MSA?

MSA usually starts between the ages of 50-60 years, although it can affect people younger and older than this. The average age of onset is 54. MSA is a disorder that occurs randomly in the general population and is considered rare (4 - 5 in 100,000). There is a slightly higher incidence in men.

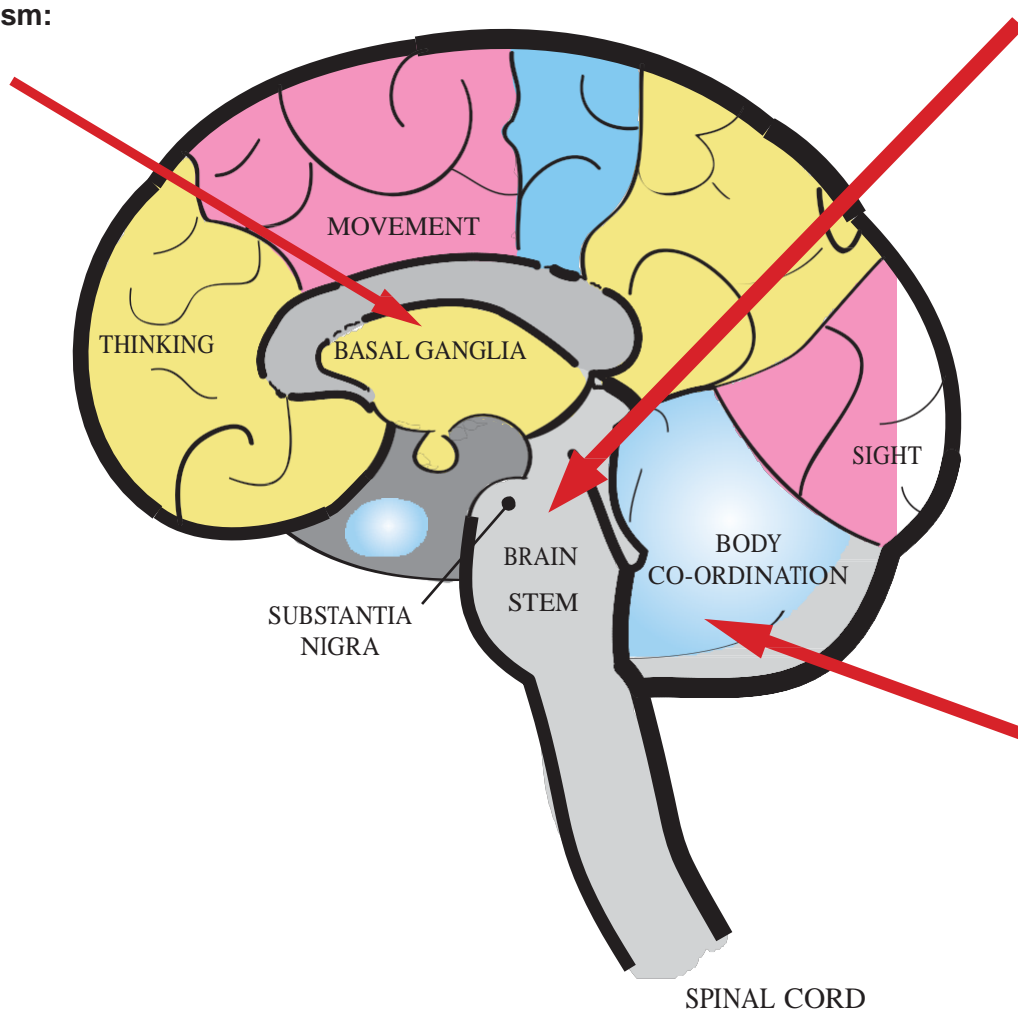
Which parts of the brain are affected in Multiple System Atrophy?

In MSA, cells are damaged in different areas of the brain which control a variety of body functions. The three areas affected are the **basal ganglia**, **cerebellum** and **brain stem**.

In MSA, brain cells in the affected areas shrink (atrophy). This can sometimes be seen on MRI scans. When brain tissue is examined under a microscope, structures called glial inclusion bodies can be seen; they contain a protein called alpha-synuclein. It is the presence of these inclusion bodies in the movement, balance and autonomic control centres of the brain that confirms a diagnosis of MSA.

Parkinsonism:

Stiffness
Slowness
Freezing



Autonomic Features:

Bladder symptoms
Constipation
Blood pressure regulation
Snoring Sleep
apnea
Erectile dysfunction

Cerebellar Features:

Balance
Co-ordination

Credit: Multiple System Atrophy Trust (UK), formerly known as The Sarah Matheson Trust used with permission www.msaweb.co.uk, 2010

What are the symptoms of MSA?

The symptoms of MSA can be put into three groups. Having a diagnosis of MSA means you have a combination of symptoms from at least two of the groups:

Parkinson symptoms – relating to slowness and stiffness of movement

- feeling slow and stiff when moving
- difficulty turning in bed
- difficulty starting to move
- difficulty fastening buttons on a shirt or blouse

Cerebellar symptoms – relating to co-ordinating movement and balance

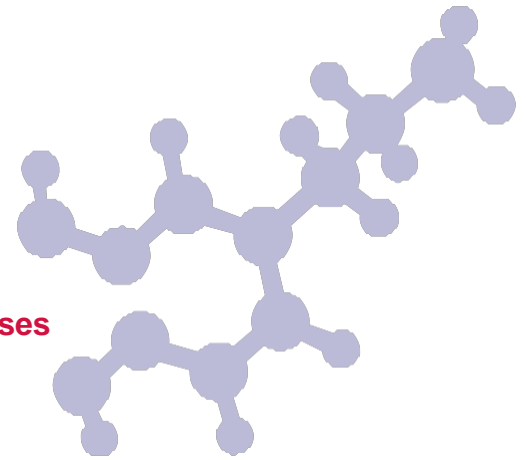
- feeling clumsy, dropping things
- feeling unsteady in crowds
- inability to balance without support
- difficulty writing
- slurred speech

Autonomic symptoms – relating to automatic body functions

- bladder problems
- erectile dysfunction
- dizziness or fainting (blood pressure problems)
- constipation
- cold hands and feet
- inability to sweat

Other symptoms may include:

- weakness in arms and legs
- heightened emotional response (laughing or crying disproportionate to the situation)
- restless sleep
- nightmares
- noisy breathing during the day, snoring at night
- unintentional sighing
- swallowing problems, difficulty chewing, choking episodes
- weak, quiet voice
- cognitive problems, slowness in thinking, difficulty with multi-tasking



What causes Multiple System Atrophy?

It is unclear why the cells become damaged in MSA. It does not appear to be inherited, although some research suggests there may be a predisposition to MSA due to the individual's genetic make-up. What triggers the damage is unknown. Environmental toxins or a history of trauma is a focus of ongoing research. MSA is not infectious or contagious.

How is someone diagnosed with Multiple System Atrophy?

Due to the variety of symptoms present in MSA, it is often difficult, at first, to differentiate it from Parkinson's disease. Sometimes, it can take years before a distinction can be made. Generally, MSA has a more rapid decline, no tremor, early autonomic symptoms, and motor symptoms on both sides of the body rather than one side. If someone responds poorly to medications used for treatment of Parkinson's disease, this may be a clue that MSA is present. Also, if you still have your sense of smell, this can distinguish MSA from Parkinson's because loss of smell is common in people with Parkinson's and not as common in MSA.

An assessment by a movement disorder specialist can determine if you have MSA. Included in this assessment would be a complete medical history, a physical exam and tests, including brain imaging.

What are the first signs of Multiple System Atrophy?

Both men and women often have bladder problems: urgency, frequency, incomplete bladder emptying or an inability to pass urine (retention). These problems may sometimes be incorrectly attributed to aging.

For men, the first sign may be erectile dysfunction (inability to achieve or sustain an erection) which may be incorrectly attributed to prostate disease.

Other problems can be dizziness on standing, fainting, difficulty turning in bed and changes in writing. Some people become clumsy or unsteady when walking, increasing risk for falls.

These early symptoms may be due to a range of other diseases which need to be excluded before a diagnosis of MSA can be made.

What is the progression of Multiple System Atrophy?

MSA is a progressive brain disease and everyone will experience MSA differently. However, the symptoms will change. In MSA, the changes occur more rapidly than with Parkinson's. You will need more help to care for yourself as symptoms impact your daily life. Lowered blood pressure can cause fainting and falls. Loss of co-ordination, slowed movements, and rigidity can interfere with activities of daily living.

How is Multiple System Atrophy treated?

Currently, there is no treatment to slow the progression of the disease. The complex nature of MSA means you should see a neurologist who specializes in movement disorders. It is important to look at and treat each symptom separately in order to maintain daily activities and quality of life. Often a multidisciplinary team, including a neurologist, social worker, speech language pathologist, physiotherapist, urologist, clinical nurse and family doctor will be involved.

What research is being done on Multiple System Atrophy?

Parkinson Canada's National Research Program includes applications for funding for MSA. Researchers around the world are looking to understand MSA to find better treatments and eventually a cure.

Suggestions that may be useful for managing symptoms of Multiple System Atrophy

Movement: Drugs to help stiffness and slowness are the same drugs used in Parkinson's disease. Medications in MSA may be effective for some people and not effective for others.

A drop in blood pressure (orthostatic hypotension): A drop in blood pressure when standing can cause dizziness, lightheadedness, fainting, or blurred vision. It may be treated with drugs that raise blood pressure. Some people find getting up slowly from a chair can reduce fainting spells. Raising the head of the bed can make it easier to get out of bed. Increasing salt in the diet and wearing pressure stockings can also help. It is important to have regular blood pressure checks.

Erectile dysfunction: Medications or penile implants may help with impotence.

Breathing: If you have problems with snoring or sleep apnea (you stop breathing while asleep), you should report this to your doctor. A breathing tube may need to be inserted.

Spasms: Medications may help treat spasms.

Constipation: Increased dietary fiber and plenty of fluids on a daily basis. Taking laxatives may relieve constipation.

Swallowing: To improve swallowing and reduce risk of choking, food may need to be pureed. If swallowing becomes difficult, a tube may be surgically inserted into the stomach.

Muscle coordination: A routine exercise program with stretching, range of movement and strength building is very important. It helps keep muscles strong and allows for safer mobility.

Urinary retention: Medications can reduce urgency and frequency problems, improve tone of bladder muscles or reduce production of urine overnight. You should take care to avoid infection and seek treatment. Consulting a urologist may help.

Health care professionals who can provide advice

Dietitian: See a dietitian for help with nutrition.

Physiotherapist: A physiotherapist can help you with gait and balance.

Occupational Therapist: See an occupational therapist for help with equipment and adaptive devices. A home-assessment to ensure your safety will help you to remain in your home as long as possible.

Speech Language Pathologist (SLP): A SLP can conduct swallowing tests and an assessment so you can avoid choking.

What do care partners need to know?

If you are a care partner or family member, MSA will affect your life, too. Learn as much as you can. Care partners often believe they will remain healthy and will always be able to provide care. However, care partners often burn out and become ill. Take care of yourself. Maintain a healthy lifestyle, including exercise and good nutrition. Consider using community services. Have an emergency plan in case you become ill. Build a network of support.

What approach can I take for the future?

Learn as much as you can about MSA. Planning ahead and talking with your care partner and family can help. Adapt your home to accommodate safety issues. Ensure you communicate with family and your health care team about your wishes (legal, financial, and personal care).

Where can I find more information?

Contact your local Parkinson for information and support or visit www.parkinson.ca.

¹Practice Parameter: Diagnosis and Prognosis of new Onset Parkinson Disease, American Academy of Neurology, 2006.
Second Consensus statement on the diagnosis of multiple system atrophy, AAN, 2008.

The contents of this document are based on information from
The National Institute of Neurological Disorders and Stroke (NINDS) www.ninds.nih.gov. WE
MOVE (Worldwide Education & Awareness for Movement Disorders) www.wemove.org/ Multiple
System Atrophy Trust (UK), formerly known as The Sarah Matheson www.msaweb.co.uk.