



Multiple System Atrophy – Guide for Staff

- Multiple system atrophy (MSA) is an adult-onset, sporadic, rapidly progressive, neurodegenerative disease.
- Accumulation of the protein alpha-synuclein causes atrophy in three parts of the brain, leading to symptoms of Parkinsonism (basal ganglia), cerebellar symptoms (cerebellar) and autonomic dysfunction (brainstem).
- People with MSA have issues with mobility, balance, motor control, dysphasia, dysphagia, bladder dysfunction (combination of urgency, frequency, nocturia and retention), neurogenic postural hypotension, altered bowel function, weakness and rigidity, REM sleep disorder, temperature regulation dysfunction, and breathing issues including stridor and sleep apnoea.
- Common reasons for admission include infection, falls, fractures or planned procedure e.g. insertion of gastrostomy.

Symptoms of MSA are made worse by infection, dehydration, constipation and disruption to usual routine. Treating reversible issues promptly is recommended.

Medications

Medications can be time critical and should be administered as per usual regimen.

If the person with MSA is unable to swallow usual medications or is Nil By Mouth, seek advice from pharmacy, neurology or Parkinson's Nurse.

Certain medications such as metoclopramide, prochlorperazine, haloperidol and hyoscine patches can be contra-indicated in MSA and specialist advice should be sought.

Surgery and Anaesthesia

If a surgery is required then assessment for consideration of spinal, epidural, nerve block, local or general anaesthetic is needed. Seek guidance regarding administration of Parkinson's medications during surgery. To assist recovery after the anaesthetic, support from physiotherapy to encourage good deep breathing and clearance of any secretions may be needed to avoid aspiration and chest infection. Stress of a general anaesthetic can cause temporary confusion that usually resolves after a day or two.

Blood Pressure

Autonomic dysfunction causes neurogenic orthostatic hypotension (nOH) in MSA. A change of position e.g. lying to standing can result in a sudden plummet in blood pressure, with significant risk of collapse / syncope. If someone has been lying down for a period time e.g. during a hospital admission or for surgery, blood pressure may drop on standing. Ensure they have had medication on time, good fluid intake and are helped to get up slowly with assistance, observing for symptoms of dizziness and syncope.

BP drop can also commonly occur when straining to open bowels or after eating. People with MSA and postural hypotension should not lie flat but sleep with the head elevated to 30 degrees. They are at risk of supine hypertension and blood pressure variability so 24-hour blood pressure monitoring may be indicated.

Lying and standing blood pressure (after a 3-minute stand) should be performed and recorded. TED stockings and abdominal binders can maintain blood pressure.

Medications such as midodrine, fludrocortisone, prydostigmine and desmopressin may be prescribed to manage BP and can be critical for management, so must be given on time.

Baseline Function

Family and regular carers should be asked about ability and baseline if it is not clear from the person with MSA themselves. An acute episode can make all symptoms worse and usual function may not be clear. Therapy staff should be involved as soon as possible with the aim of preserving baseline, especially with regards to mobility, which can be lost quickly if not maintained.

Communication and Cognition

People with MSA can have dysarthric and dysphasic speech; they may have a high-pitched ataxic voice, a quiet voice or no speech at all. They may use low-tech or high-tech communication aids that the patient might need help to access and use.

Often people with MSA need to concentrate on one thing at a time. Give time for people to think and respond. Cognitive changes can cause slowness of thought, difficulty with recall and word-finding and other language difficulties. Changes to executive function can mean learning to use new things can be difficult and risk isn't always appreciated.

Cognition is usually such that they know what is going on around them and what they would like to say. Family members can help due to familiarity. People with MSA do not commonly experience dementia and retain the ability to make informed decisions in most cases.

Hallucinations are not common in MSA and when they occur they are likely to be the result of an infection or as a side effect of medication. Treating the underlying cause should resolve acute episodes of hallucination or delirium. Haloperidol and some other anti-psychotics should be avoided in MSA.

Additional Points

- Many people with MSA have REM sleep disorder, impaired oxygenation overnight and sleep apnoea. They may be on CPAP. They commonly need to be up several times to the toilet. Poor sleep quality adds to the overwhelming fatigue that is a core symptom of MSA and this too impairs functionality and increases frustration and risk of falls.
- Autonomic dysfunction can mean a person with MSA **may not have a raised temperature with an infection**. Other measures such as urine and blood tests should be used to test for infection as temperature is not a reliable measure in MSA.
- Constipation makes all other symptoms of MSA worse and can impede absorption and efficacy of medications, especially Parkinson's medications.
- Sit out and mobilise ASAP to prevent deterioration in function and prevent blood pressure from dropping.
- Involve the patient's usual care team by liaising with the Consultant, the Neurology team and their Parkinson's, Neurology or Movement Disorder Nurse Specialist.

Discharge planning should consider that MSA is progressive condition with no remission and a hospital stay can often result in a new baseline if return to previous function is not achievable, especially if there has been significant immobility. Efforts should be made to maintain function, but discharge planning needs to consider if needs have changed and if further care support or equipment is needed to ensure safe and successful discharge.

The Multiple System Atrophy Trust can provide information and support to Health Care Professionals caring for people with MSA. Please contact the MSA Trust on 0333 323 4591 or email support@msatrust.org.uk to be put in touch with a MSA Health Care Specialist (available Monday-Friday, 9am-5pm).

People living with MSA developed the 'above-bed' sign overleaf, to be used with the permission of the person living with MSA.



Multiple System Atrophy

My movement, coordination and bodily functions are affected

Please give me time and help me to:

Mobilise:

- Walk regularly, if I can, with the support and aids I need
- Sit in a chair with good postural support

Be heard:

- Listen carefully – my speech might be quiet
- Assist me to access and use any communication aids I have
- Ensure I can use the call system

Access the toilet:

- I need to sit and be well supported on the commode or over the toilet
- I am high risk for being constipated

Keep hydrated and well nourished

- Sit, with posture supported, at the table
- Have food and drink I can safely manage to swallow
- Positioned so I can feed myself or have assistance if I need it