



## TOP TEN LESSER-KNOWN THINGS ABOUT MULTIPLE SYSTEM ATROPHY

These are things not normally highlighted in traditional literature about Multiple System Atrophy. The Multiple System Atrophy Coalition compiled this list by drawing upon the collective experience (since 1995) of hundreds of members of the MSA Shy-Drager online support group founded by Vanderbilt University Autonomic Dysfunction Center staff. <http://groups.yahoo.com/group/shydrager>

**1. WATCH FOR SLEEP AND BREATHING PROBLEMS:** Sleep and breathing problems are very common in MSA patients. Sleep apnea (momentary lapses in breathing), respiratory stridor (noisy breathing), REM behavior disorder (shouting and acting out dreams) and excessive daytime sleepiness can be among the earliest symptoms of MSA. Sleep apnea is very serious and can lead to sudden death during sleep. Ask your bed partner if you snore, breathe loudly in your sleep, talk in your sleep or act out your dreams. Ask to be referred to a sleep specialist for a sleep study often this can be performed in your own home. Not getting a good night's sleep can make other MSA symptoms seem worse both for the patient and the caregiver. Sleep and breathing problems can be easily treated with a CPAP or Bi-Pap - this is a mask with pressurized air worn at night.

**2. BE AWARE OF SITUATIONS THAT CAN AFFECT BLOOD PRESSURE:** Blood pressure can DROP suddenly (hypotension) in several situations: 1. After getting up in the morning - drink a large glass (12 oz or more) of plain water before getting out of bed to raise your blood pressure and take your morning medications and wait 15-20 minutes to allow them time to work before getting up. 2. During a bowel movement - use a footstool in front of the toilet to keep your legs up and your blood pressure up. 3. After a large meal - eat 5 or 6 small meals instead of larger meals. 4. After standing in one place for a long time - sit whenever possible TIP: If someone feels faint or passes out, lay them down and elevate their legs above the level of the heart. Blood Pressure can also SPIKE UPWARD (hypertension) in several situations: 1. When lying flat (supine) during sleep - raise the head of the bed 4 to 6 inches higher than the foot of the bed at night to help prevent this. TIP: If the blood pressure is too high while laying down, sitting up or standing can bring it back down quickly. Remind your doctors that they should not overreact to a high supine blood pressure.

**3. PREVENT INFECTIONS:** MSA patients often register a body temperature that is a degree or more below normal. Because of this a fever may not be detected. Any sudden worsening of symptoms or confusion could be a sign of infection. An even lower temperature than the normally (MSA) low temperature can also be a sign of infection. Be vigilant about preventing and detecting all types of infections urinary tract (UTI) and lung infections (PNEUMONIA) are very common. Stay well hydrated (64 oz fluid per day) to prevent urinary tract infections. Stay dry and shift weight often to prevent skin pressure sores. Swallow carefully to avoid choking and aspiration. Puree foods when swallowing becomes difficult. Get speech and swallowing therapy to avoid aspiration pneumonia. Watch for bowel blockage from chronic constipation.

**4. BE CAREFUL OF SURGERY/ANESTHESIA:** If an MSA patient is to have any dental work or surgery, a local anesthetic should be the preferred choice if possible. However, some local anesthetics contain adrenaline which may adversely affect blood pressure. Ensure that the dentist or surgeon and anesthesiologist know that MSA affects the autonomic nervous system. The MSA patient must be well hydrated via IV before and during surgery to maintain a safe blood pressure. Another note on surgery: Prostate surgery should only occur if the urologist and neurologist have had a consultation with each other and agree that prostate enlargement is the cause of urinary retention (since this is a common symptom of MSA which does not improve with prostate surgery).

DISCLAIMER: This information is intended to aid MSA patients and their families in their discussions with clinicians. It should not be considered medical advice or endorsements of drugs or therapies. Always consult a licensed medical practitioner for expert care.



**5. BE CAREFUL WITH OVER-THE-COUNTER COLD/FLU/ALLERGY MEDICATIONS:** Many of these medications contain pseudoephedrine that can affect the heart and raise blood pressure, to dangerous levels. They also may interact with prescribed medications. Be very careful and consult your doctor before mixing any medications, including over-the-counter remedies or even vitamins.

**6. PREVENT FALLS:** Preventing falls is very important, if you fall and break a bone you may become bedridden and more prone to infections. When it becomes appropriate use a cane, walker or wheelchair. Install grab bars in the bathroom, use a raised toilet, use a shower chair or bench, use a Hoyer lift for transfers.

**7. AVOID EXTREME HEAT OR COLD:** MSA can affect the body's ability to sweat and to maintain a proper core temperature. It's important to stay cool during hot or humid weather and stay warm during cooler weather. Also avoid very hot baths and showers.

**8. EXERCISE!** It's important to maintain strength and flexibility for as long as possible. Do range of motion exercises and any gentle exercise that can be done when sitting. Water exercises are easy to do and very helpful. Practice speech exercises along with the other exercises to help maintain strength and clarity of voice for as long as possible. Ask for physical and occupational and speech therapy as these are all known to be beneficial to MSA patients.

**9. PREPARE FOR EMERGENCY ROOM VISITS:** Keep a short description of your medical history, a description of MSA, and your most recent medications list handy so you can take it with you to any new doctors' appointments, hand it over in an emergency room, give it to caregivers, etc. If you are in any of those situations, it's much easier to have something pre-prepared, especially if you're talking to people who have never heard of MSA.

**10. BE READY TO ADVOCATE AND TO COORDINATE A TEAM OF DOCTORS:** Be ready to "advocate" with your doctors, or ask a trusted friend, family member or caregiver to play this role. MSA is a complex disorder and not every doctor will have heard of it, find a doctor you trust who is willing to learn. There is literature available and there are known MSA expert neurologists who can act as consultants. At each appointment try to focus on 1 or 2 concerns to get them addressed adequately. Have a buddy with you who will make sure you are heard! Often your general practitioner can help play the coordinator role by referring you to other experts such as a neurologist, internist, cardiologist, urologist etc. If you are participating in research studies or if you are using health supplements, let all your doctors know about this.

Also, you should spend some time thinking about your "advance directives" and make it clear to your family members, caregivers and health care providers if you have made a decision about which emergency treatments you want or don't want (such as resuscitation, intubation or feeding tubes). Remember that you can ALWAYS change your mind and change your advance directives.

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For more information, please see the Multiple System Atrophy Coalition website [www.MultipleSystemAtrophy.org](http://www.MultipleSystemAtrophy.org) or call the toll-free support line 1-866-737-5999

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