



The MSA Journey

Appendices:

Worksheets and Other Tips



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Defeat MSA Alliance has used all reasonable care to present accurate information and to provide a careful summary about possible symptoms and known treatments. If you should see anything that you believe is missing, inaccurate or have any further suggestions to include our next edition, please feel free to reach out to Defeat MSA Alliance to help: info@defeatmsa.org

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*You give but little when
you give of your possessions.
It is when you give of yourself
that you truly give.*

– Kahlil Gibran

PLEASE NOTE

In the next pages you will find some worksheets and documents with helpful tips. However, you can find a complete portfolio with downloadables, including Power of Attorney (POA) and Healthcare POA samples on our website (https://www.defeatmsa.org/caregiver_pages) or The MSA HUB (<https://msa-hub.circle.so/>)



EMERGENCY CONTACT LIST



Complete the form below and bring it with you to doctor's visits and emergency room visits.

IN CASE OF EMERGENCY, USE THE INFORMATION BELOW

Neurologist

Name _____

Address _____

Phone number _____

Primary Care Physician

Name _____

Address _____

Phone number _____

Preferred Hospital

Name _____

Address _____

Phone number _____

Pharmacy Info

Name _____

Address _____

Phone number _____

Emergency Contact Info

Name _____

Address _____

Phone number _____

Emergency Contact Info

Name _____

Address _____

Phone number _____

Healthcare Appointment Preparation Guide



Appointment Details		
Provider name:	Date: _____	Time: _____
Provider Type:		
Goals for Appointment:		
Follow-up for Appointment:		
Medication Changes:		

Questions for Provider	
Question #1:	
Notes:	

Question #2:	
Notes:	

Question #3:	
Notes:	

Additional notes:

TOP TEN THINGS YOU NEED TO KNOW ABOUT MSA

1. PREVENT INFECTIONS:

MSA patients often register a body temperature that is a degree above or 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 usual can also be a sign of infection. Be vigilant about preventing and detecting all types of infections. Urinary tract (UTI) and lung infections, such as 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, help avoid choking and aspiration. Puree foods when swallowing becomes difficult. Get speech and swallowing therapy to avoid aspiration pneumonia.

2. 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 Continuous Positive Air Pressure (CPAP) or a Bi-Pap, this is a mask with pressurized air worn at night.

3. BE AWARE OF SITUATIONS THAT CAN AFFECT BLOOD PRESSURE:

Blood pressure can DROP suddenly (this is called hypotension). Here are some possible suggestions for resolving hypotension: (a) After getting up in the morning – drink a large glass of water before getting out of bed to raise your blood pressure. (b) During a bowel movement – use a foot stool in front of the toilet to keep blood pressure up. (c) After a large meal—eat 5 or 6 small meals instead of larger meals. (d) After standing in one place for a long time – sit whenever possible. Blood Pressure can SPIKE UPWARD suddenly (hypertension): 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 may help to prevent this. Further note on blood pressure: If a patient's blood pressure is too high laying down then simply sitting them up may help bring it back down.

4. BE CAREFUL OF SURGERY/ANESTHESIA:

If an MSA patient is to have any dental work or surgery, a local anesthetic may be the preferred choice if possible. Consult the doctor. However, be aware of local anesthetics with adrenaline or derivatives. Ensure that the dentist or surgeon and anesthesiologist know that MSA affects the autonomic nervous system. The MSA patient should 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.

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, leading

to stroke. 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 an MSA patient falls and breaks a bone, he or she may become bedridden and therefore, more prone to infections. When it becomes appropriate, use a cane, walker or wheelchair. Installing grab bars in the bathroom, using a raised toilet, using a shower chair or bench, using a Hoyer lift for transfers are all good suggestions.

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 for the patient to stay cool during hot or humid weather and stay warm during cooler weather. Also, avoiding very hot baths and showers could be helpful to moderate body temperature.

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 could be 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 possibly beneficial for 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 very often, many doctors will not have ever heard of it. Find a doctor you trust who is willing to learn about MSA. There is medical literature available to medical providers 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're 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.

"Out of suffering have emerged the strongest souls; the most massive characters are seared with scars."

- Kahlil Gibran

THINGS I LEARNED BY VICKY S. & OTHER TIPS FOR THE CAREGIVER

If You Are Not Yet a Caregiver:

- Never use a handicapped stall, if any other is available!
- Live beneath your means, so you can stop working to care later if needed.
- If married or partnered, understand and commit to “in sickness and in health.”
- If you are lucky enough to have your parent with MSA still with you, realize that this is what it means to care for one’s parent. They brought you into the world, duty calls, most times at an unexpected time.

When Duty Calls: The Fundamental Attitude of the Caregiver:

- “Goodbye tomorrow, hello today.”
- Margaret Mead said that caregiving is the first sign of civilization in a culture. Helping someone else through difficulty is where civilization starts. We are at our best when we serve others. This is what sets us apart from other animals.
- You will repeatedly bump up against the brink of what you think you can’t handle, and then you handle it. Because you can.
- Early on, especially, there’s a struggle between what’s happening/what you’re dealing with, and what you don’t want to have to deal with. It may feel like no good can come from end of life caregiving because there will be a terribly sad end, and the path there could be brutal. Work to get to a place where providing the care inspires you.
- Prepare for a marathon, one with no known ending. Don’t reflect back, don’t look forward, live in the moment.
- Every day is a test. Some days you’ll pass the test and other days you’ll...learn from the test. Every day you take the test. When you feel as though you didn’t pass, forgive yourself. Start over the next moment, hour or day.
- Learn to transition faster through the downshifts. Your loved one may suddenly not be able to...help you, bathe, dress, do their nails, floss, read, eat, remember....How you react will have an impact. So transition quickly, and cope privately.
- Prepare for prolonged grief, endlessness, loneliness. But do have faith and remember: you have people who support you, somewhere, somehow.
- “Take care of yourself” they’ll say. What does that look like when you’re a full-time caregiver? Find small moments to care for yourself: Exercise if you have a free minute. If you can’t sleep, read something you enjoy. Play music in the kitchen. Accept food and help.
- Regardless of issues you may have had or have with your loved one, choose to rise to the opportunity, each opportunity, to care. Act in a way that you will be proud of later. Try to remember that if they hurt you, it may be the disease not the patient.
- Expect nothing of anyone. Friends and family will surprise you on the upside and, sadly, sometimes also the downside. Old friends, new friends, present friends, absent friends. Learn to welcome it, and/or let it go.
- Embrace the idea of professional hired help earlier than you want to, so you are more available for your loved one, and for yourself.

- There is something spiritual in caregiving.
- Get to where you can try to find joy in the moment and enjoy the moment, rather than tolerating the moment. Find/feel purpose in what you're doing, not what you are missing.
- Change your goals and plans: let go faster than you want to of what you thought you'd do/your days/life would be like. Look for beauty in the routine and simple. Live in the moment.
- Be prepared to measure success differently. Master caring. Master giving. Master caregiving. Master creating comfort. Master creating peace. Master managing your reactions to people who hurt you. Imagine if this is it, all there's ever going to be, make it matter ...If this is your life, it matters. Come to believe: "This is my life. I embrace this."

The Brass Tacks

- Keep notes always and always keep notes.
- Keep a journal (on your phone, at your bedside or in the kitchen) of symptoms: physical, emotional, cognitive. It'll help you decipher what's happening, see patterns, and learn how to respond better and faster. Especially if you are still looking for a diagnosis or if there are cognitive issues.
- Keep notes on medications (current and past), test results and/or numbers.
- Start a list of what people can do for you, if they ask. Weed the garden? Plant a plant? Run an errand? Check in with you when they head to the grocery store? Make a meal that can go straight into the freezer for future days.
- Keep a list of what the patient will/won't eat. Tastes may change. If people offer to bring food, ask to share ideas on what to bring/not bring.
- Keep a note of inspiring/comforting quotes about caregiving to lift your spirits when needed.

Physical Caregiving, Tools and Resources

- Find an online care group, visit <https://defeatmsa.org/patient-programs/#facebook-online-groups>. Members will share honestly and confidentiality is the strict rule. In the group, you will realize that you are not alone. You'll find questions, get ideas, help plan for the future, help cope with the day-to-day or minute-to-minute. You may not have time for any other help. This may be the first place you go in the morning or the last moment before bedtime. Sometimes, these may, at times, be the only people you want to connect with because they understand what you are experiencing. WE SHARE YOUR STRUGGLE! We are all in this same club, unfortunately, and it's a club no one ever wanted to join – but we are here now, and we will support you! We owe it to those we have lost – we will continue to defeat MSA in their honor.
- Take advantage of the Annual Defeat MSA and MSA United All-Community Conferences, sign up for the newsletter at Defeat MSA to stay in contact: <https://defeatmsa.org/subscribe/>
- Register on the **MSA Hub**. Started in 2018, it is an alternative to Facebook, a place for the MSA community to connect with and inform themselves about everything MSA: diagnosis, treatment, research, drug trials, advocacy, awareness and even creative self-expression.
- Learn or adopt physical caregiving skills you may need before you need them. If you're ever in a hospital, watch how nurses and assistants move, roll, clean and care for patients in bed. Search for training videos on-line, try the resources at DefeatMSA.org to learn more about caregiving.
- Be ahead of safety needs: Walker/wheelchair combo, lightweight transport wheelchair, heavier transport wheelchair with larger rear wheels, stairlifts, grab bars in bathrooms and outer doorways, floor to ceiling pressure mounted transfer poles, hoists or lift devices, ramps, toilet to shower transfer chair, cloth bed pads with handles, vinyl transfer sheets, foam cushions for patient support, reclining wheelchairs (for MSA

patients in orthostatic hypotension), reclining commodes (for the same as previous), thickened liquids to avoid aspiration, etc.

- Ask for palliative care or pain management when you think you need it.
- If you can, hire extra help. Consider respite care for 1-2 times a week for the bed time routine or morning help.

If Cognitive Issues Arise:

- Understand confabulation. “Confabulation is a type of memory error in which gaps in a person’s memory are unconsciously filled with fabricated, misinterpreted, or distorted information. When someone confabulates, they are confusing things they have imagined with real memories. A person who is confabulating is not lying.” Confabulation may occur in patients with MSA or other neurodegenerative disorders.
- Keep notes to understand patterns and triggers, and to keep from losing your mind.
- This may feel like quicksand, or “fun house” mirrors, but there’s nothing fun about it. Be prepared for dark days and sometimes, the dark nights.
- You or they may not be able to read emotions, and may misread reactions: fatigue could be seen as anger, calm as disinterest. Sad becomes unhappy. Sarcasm can’t be read. Speak in black and white. Work very hard to remain calm and kind in tone and words. Peace begets peace. Patience begets patience.
- Let go of the expectation that your loved one will necessarily be able to communicate on a typical or former level. Listen for little messages, subtle messages. Understand your loved one may feel confused on the inside. Your loved one may have trouble thinking, following conversations or expressing.

Prepare for the Future

- Start asking your loved one questions, for a Q and A about their lives, feelings and memories to share with their children and grandchildren.
- Encourage your loved one to write letters of love to those they love. For some, these may of immense value to family and friends.
- If your MSA warrior is receptive, it is good to discuss his or her final wishes.
- Make sure beneficiary designations are current well before the end, including for any inherited IRAs.
- Have a list of ALL assets, life insurance policies, bank and investment account numbers, retirement accounts, locations of ownership papers. Have birth certificate, marriage certificate, full names of parents, advisors, phone numbers.
- Have access to passwords (if worried about privacy they can put in a sealed envelope).
- Talk more than you may want to, because life is short, and you may never get another chance. Tell them you love them, ask what they want you or others to know.

Commit to volunteering or fundraising in honor of a loved one.

Contact Defeat MSA for Ideas, Options or Help:

Email us: info@defeatmsa.org

Tel: 855-542-5672 (855 Kick-MSA)

*“The first duty of love is to listen.”
- Paul Tillich*



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