



Multiple System Atrophy TOP RESOURCES

Brain Support Network (BSN) has reviewed most of the resources available on MSA. In our opinion, these are the most helpful family resources.

MSA Symposium

This 4.5-hour event features an autonomic disorder specialist, movement disorder specialist, physical therapist, speech therapist, neuro-palliative care expert, and BSN's Robin Riddle about brain donation. A highlight is a panel moderated by BSN's Candy Welch with three caregivers, a woman with MSA-C, and a man with MSA-P. Webpage includes recordings, speaker slides, notes, resource list, and MSA quiz. May 2024, co-hosted by Stanford and Brain Support Network.

> brainsupportnetwork.org/msa-symposium

Top Ten Things You Need to Know About Multiple System Atrophy

Two-pager compiled from posts to now-defunct online MSA-related support group. These ten items are not normally highlighted in MSA literature.

> brainsupportnetwork.org/MSA-Awareness-10-things-to-know-about-MSA.pdf

MSA: Some Answers

Short brochure by CurePSP. Last updated in 2023.

> psp.org/assets/resources/items/65d60110be43aMSA-SOME-ANSWERS-2023.pdf

Your Essential MSA Guidebook

This 27-page booklet outlines how MSA is diagnosed, symptoms, stages, gathering a care team, and planning. Produced by Mission MSA. Published April 2024.

> missionmsa.org/resource-library/your-essential-msa-guidebook

Fact Sheets

The MSA Trust (UK) has 39 fact sheets on topics such as bowel management, continence, fatigue, Parkinson's medications, monitoring blood pressure, saliva, driving, and hygiene equipment.

> Main page: msatrust.org.uk/support-for-you/factsheets/

Brain Support Network's MSA blog

Blog posts include tips by those with MSA and caregivers. Website offers a list of top resources on MSA, the latest diagnostic criteria, and a short overview of the disorder.

- > MSA Blog: brainsupportnetwork.org/category/msa/
- > MSA Information: brainsupportnetwork.org/education/multiple-system-atrophy/

Carer's Guide

Includes a list of things of practical, physical, and emotional aspects of caring for someone with MSA. Revised March 2022. By the MSA Trust (UK).

> msatrust.org.uk/wp-content/uploads/2015/11/BK050-Carers-Guide-V3.1.pdf

Multiple System Atrophy: What Is It, Causes, Symptoms, and More

Short webpage for physicians wanting to learn about MSA. Consider sharing link and helpful summary image, with your primary care physician.

> osmosis.org/answers/multiple-system-atrophy

MSA Brain Donation: Confirm Diagnosis, Support Research for a Cure

Brain Support Network's Robin Riddle speaks on the benefits of brain donation for MSA.

- > May 2024 (10 min): http://youtu.be/1KOBG06SBg8?si=tZHzsE6sdl2fgnjg
- > March 2021 (50 min): youtu.be/9QDnBhi3U g?t=241

Recent MSA Patient/Family Conference

Unedited conference recordings from the MSA Coalition's (now Mission MSA) all-day event.

> 2022 (50 videos): youtube.com/playlist?list=PLXIIQK13JCsH16Cb98a-g_BDmu51mj2nc

Treating PSP, MSA, and CBD – What can be done?

Movement specialist Dr. Brent Bluett describes the symptomatic treatments that can improve quality of life. February 2019 webinar, co-hosted by Stanford and Brain Support Network.

- > Detailed notes: brainsupportnetwork.org/treating-psp-msa-and-cbd-webinar-notes-recording-resources
- > Recording: youtube.com/watch?v=ePKXO1UPOlw

Orthostatic Hypotension (OH) in PD, MSA, and LBD

Movement specialist Dr. Veronica Santini describes OH and treatment (conservative approaches and medication). September 2017 webinar, co-hosted by Stanford and Brain Support Network.

- > Detailed notes: brainsupportnetwork.org/notes-orthostatic-hypotension-pd-msa-lbd-webinar/
- > Recording: youtu.be/-FzsgUfQ_xl

Evaluating and Treating Urinary Issues in PD, MSA, etc.

Urologist Dr. Ekene Enemchukwu focuses on urinary incontinence, overactive bladder, urinary retention, nocturia, etc. August 2019 webinar, co-hosted by Stanford and Brain Support Network.

- > Detailed notes: brainsupportnetwork.org/evaluating-treating-urinary-issues-in-pd-msa-etc-webinar-notes-recording-resources/
- > Recording: youtube.com/watch?v=rPulXhZYaX8

MSA and Cognition

Movement specialist Dr. Kathleen Poston describes cognitive aspects of MSA. November 2018 webinar, co-hosted by Stanford and Brain Support Network.

- > Detailed notes: brainsupportnetwork.org/multiple-system-atrophy-cognition-webinar-recording-resources-notes/
- > Recording: youtube.com/watch?v=hr0TCWqBgUY