



Multiple System Atrophy **TOP RESOURCES**

Brain Support Network has reviewed most of the resources available on Multiple System Atrophy (MSA). In our opinion, these are the most helpful family resources. Download at www.brainsupportnetwork.org/BSN-MSA-resources-2018-09.pdf

A Guide to Multiple System Atrophy

This 36-page guide, last revised in November 2015, was written by the Multiple System Atrophy Trust in the UK. It offers a short description of MSA and details on treatment and management of symptoms.

www.msatrust.org.uk/wp-content/uploads/2015/11/A-Guide-to-MSA.pdf

Multiple System Atrophy

Written by the National Institutes of Health (NIH) and revised in November 2014.

Fact sheet: www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Multiple-System-Atrophy (Also available in Spanish)

Top Ten Things You Need to Know About Multiple System Atrophy

Two-page document compiled by MSA Awareness from posts to an online MSA-related support group. These are 10 items not normally highlighted in MSA literature.

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

MSA: Some Answers

This short brochure was published by CurePSP and last printed in October 2017.

www.psp.org/wp-content/uploads/2017/09/MSA-SOME-ANSWERS-BROCH_PAGES_WEB-9.19.17.pdf

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

Brain Support Network volunteer Robin Riddle spoke in September 2018 at the MSA Coalition Conference about how brain donation has benefited MSA research.

www.brainsupportnetwork.org/MSABrainResearch_0918.pdf

Orthostatic Hypotension (OH) in Parkinson's Disease (PD), Multiple System Atrophy (MSA), and Lewy Body Dementia (LBD)

Dr. Veronica Santini describes the symptoms of OH, lists the conservative and medication interventions, and answers questions. This September 2017 webinar was co-hosted by Stanford University and Brain Support Network. Detailed notes:

www.brainsupportnetwork.org/notes-orthostatic-hypotension-pd-msa-lbd-webinar/

Recording: www.youtube.com/watch?v=-FzsgUfQ_xl

Recent MSA Patient/Family Conferences (Nashville and New Orleans)

There were many terrific speakers at the MSA Coalition's October 2017 and 2016 all-day events. Note in particular Dr. Allyson Mayeux's keynote address in October 2016 about her brother Hal's journey, ending in brain donation. Unedited recordings:

2017: www.multiplesystematrophy.org/annual-msa-patient-family-conference-2017-videos

2016: www.multiplesystematrophy.org/2016-msa-patient-family-conference-live

Slides from 2017: www.multiplesystematrophy.org/resources/msa-patient-family-conference-handouts

Recent MSA NJ Patient/Family Conference

There were many terrific speakers at MSA NJ's March 2018 and 2017 all-day conferences. Note in particular the talks on practical methods and "toolbox kit."

2018: msanj.org/2018-regional-patient-and-caregiver-support-conference/

2017: www.youtube.com/playlist?list=PLA6kMi603zp3ADJNmKKgdbKtE2GL4UGwH

MSA: What You Need to Know

This 57-page document from 2014 is a look at treatment of common symptoms.

multiplesystematrophy.org/wp-content/uploads/2014/07/MSA_-_What_You_Need_to_Know_v2.pdf

Treatment of and Research on Multiple System Atrophy

Movement disorder specialist Dr. Kathleen Poston gave an indepth presentation on MSA as part of an atypical parkinsonism symposium organized by Stanford University and Brain Support Network in October 2012.

www.youtube.com/watch?v=osgaPBrB95E

Fact Sheets

In 2015, the Multiple System Atrophy Trust in the UK published 25 fact sheets on topics such as bowel management, continence, fatigue, Parkinson's medications, monitoring blood pressure, saliva, driving, and useful equipment for hygiene.

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

Carer's Guide

This short guide, published in June 2014, was written by the Multiple System Atrophy Trust in the UK. It includes a list of things to think about early on -- practical aspects, physical aspects, and emotional aspects of caring for someone with MSA.

www.msatrust.org.uk/wp-content/uploads/2014/06/MSA-Trust-Carers-Guide_v1.0.pdf

Brain Support Network's MSA blog and web pages

See BSN's MSA blog here: <https://www.brainsupportnetwork.org/category/msa/> Get these blog entries in your email box here: www.brainsupportnetwork.org/about-bsn/join-our-email-list/

See BSN's web pages on MSA:

www.brainsupportnetwork.org/education/multiple-system-atrophy/