



## 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-2019-09.pdf](http://www.brainsupportnetwork.org/BSN-MSA-resources-2019-09.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](http://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](http://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](http://www.brainsupportnetwork.org/MSA-Awareness-10-things-to-know-about-MSA.pdf)

### **Treating Progressive Supranuclear Palsy (PSP), Multiple System Atrophy (MSA), and Corticobasal Degeneration (CBD) – What can be done?**

Dr. Brent Bluett describes the symptomatic treatments possible for MSA that can improve quality of life. Each individually may be minor, but in same they can make a significant difference. There is always hope! This February 2019 webinar was co-hosted by Stanford University and Brain Support Network. Detailed notes:

[www.brainsupportnetwork.org/treating-psp-msa-and-cbd-webinar-notes-recording-resources](http://www.brainsupportnetwork.org/treating-psp-msa-and-cbd-webinar-notes-recording-resources)

Recording: [www.youtube.com/watch?v=ePKXO1UPOlw](http://www.youtube.com/watch?v=ePKXO1UPOlw)

### **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/](http://www.brainsupportnetwork.org/notes-orthostatic-hypotension-pd-msa-lbd-webinar/)

Recording: [www.youtube.com/watch?v=-FzsgUfQ\\_xI](http://www.youtube.com/watch?v=-FzsgUfQ_xI)

## **Evaluating and Treating Urinary Issues in Parkinson's Disease (PD), Multiple System Atrophy (MSA), and Other Atypical Parkinsonism Disorders**

Dr. Ekene Enemchukwu focuses on urinary incontinence, overactive bladder, urinary retention, nocturia, and other urinary issues. This August 2019 webinar was co-hosted by Stanford University and Brain Support Network. Detailed notes:

[www.brainsupportnetwork.org/evaluating-treating-urinary-issues-in-pd-msa-etc-webinar-notes-recording-resources/](http://www.brainsupportnetwork.org/evaluating-treating-urinary-issues-in-pd-msa-etc-webinar-notes-recording-resources/)

Recording: [www.youtube.com/watch?v=rPulXhZYaX8](https://www.youtube.com/watch?v=rPulXhZYaX8)

## **Recent MSA Coalition Patient/Family Conferences**

There were many terrific speakers at the MSA Coalition's all-day events in 2014-2019. Note in particular Dr. Allyson Mayeux's keynote address in October 2016 about her brother Hal's journey, ending in brain donation. List of unedited recordings:

[www.multiplesystematrophy.org/msa-resources/annual-conference/2019-msa-coalition-conference-educational-session-videos/](http://www.multiplesystematrophy.org/msa-resources/annual-conference/2019-msa-coalition-conference-educational-session-videos/)

## **Recent MSA NJ Patient/Family Conference**

There were many terrific speakers at MSA NJ's 2018 and 2019 all-day conferences.

2019: [www.msanj.org/2019-conference/](http://www.msanj.org/2019-conference/)

2018: [www.msanj.org/2018-regional-patient-and-caregiver-support-conference/](http://www.msanj.org/2018-regional-patient-and-caregiver-support-conference/)

## **MSA: What You Need to Know**

This 53-page document from April 2019 looks at treatment of common symptoms.

[www.multiplesystematrophy.org/wp-content/uploads/2019/09/What-You-Need-to-Know-9.4.19-DSC-AM-NV-Edits2.pdf](http://www.multiplesystematrophy.org/wp-content/uploads/2019/09/What-You-Need-to-Know-9.4.19-DSC-AM-NV-Edits2.pdf)

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

Brain Support Network's Steven Russell spoke in September 2019 at the MSA Coalition Conference about how brain donation has benefited MSA research.

[www.brainsupportnetwork.org/BSN-at-MSA-Family-Conf-2019-0927.pdf](http://www.brainsupportnetwork.org/BSN-at-MSA-Family-Conf-2019-0927.pdf)

## **Fact Sheets**

In 2015, the Multiple System Atrophy Trust in the UK published 25 fact sheets.

Main page: [www.msatrust.org.uk/support-for-you/factsheets/](http://www.msatrust.org.uk/support-for-you/factsheets/)

## **Carer's Guide**

Published in June 2014 by the Multiple System Atrophy Trust in the UK.

[www.msatrust.org.uk/wp-content/uploads/2014/06/MSA-Trust-Carers-Guide\\_v1.0.pdf](http://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 inbox here: [www.brainsupportnetwork.org/about-bsn/join-our-email-list/](http://www.brainsupportnetwork.org/about-bsn/join-our-email-list/)

See BSN's web pages on MSA:

[www.brainsupportnetwork.org/education/multiple-system-atrophy/](http://www.brainsupportnetwork.org/education/multiple-system-atrophy/)