

Patient Journeys are **info-graphical overviews** that visualize patients' needs in the care of their rare disease.

Because Patient Journeys are designed from the **patient's perspective**, they allow clinicians to **effectively address the needs** of rare disease patients.

Find a detailed version of this patient journey on our website.

Overview	Patient Journey Multiple System Atrophy (MSA)			
Topic	1. First symptoms	2. Diagnosis	3. Treatment	4. Monitoring
Disease	<p>Presentation after the age of 50 years, average age of onset between 50–60 years, disease onset is &gt; 20 years, MSA is a multiple disease with 5 or 7 key symptoms.</p> <p>First initial symptoms are subtle and non-specific.</p> <p>Symptoms fall in two categories:</p> <ul style="list-style-type: none"> <li><b>motor symptoms</b> - include urinary and/or bladder control, balance problems, slowness of movement, shuffling and/or freezing, irregular control of the limbs, parkinsonian symptoms are poorly responding to treatment</li> <li><b>autonomic nervous system symptoms</b>, which are involuntary processes, e.g. heart rate, blood pressure, sweating, vision, bowel and sexual function</li> </ul> <p>Additionally, other symptoms may include uncontrollable laughing or crying (pathological emotional lability), sleep disturbance, loss of consciousness, weight loss, rapid weight loss, quiet voice.</p>	<p>The difficulty of MSA lies in the range of symptoms requiring the setting up of a timely monitoring system at neurological clinics.</p> <p>MSA is a clinical diagnosis and is subdivided into:</p> <ul style="list-style-type: none"> <li>MSA with Parkinson (MSA-P) - parkinsonism of movement, rigidity and bradykinesia</li> <li>MSA with cerebellar (MSA-C) - ataxia with balance, first motor movements and speech are affected</li> </ul> <p>Different levels of diagnostic certainty were defined in the latest international diagnostic criteria:</p> <ul style="list-style-type: none"> <li>Clinically established MSA</li> <li>Probable MSA</li> <li>Possible MSA</li> </ul> <p>In the second phase of MSA disease development, the frequency of medical actions of individual symptoms at various times increases (insomnia, breathing, cough, constipation, urinary incontinence, gait, swallowing, vision, bowel and sexual function).</p> <p>A definitive diagnosis of MSA is only possible from examining the brain cells from different parts of the brain under a microscope.</p> <p>The multiplicity of MSA in clinical practice raises the key question of managing the clinical diagnosis and maintenance treatment of the underlying symptoms of MSA.</p> <p>The location of the symptoms is most effective within:</p> <ul style="list-style-type: none"> <li>diagnostic</li> <li>speech therapy problems</li> </ul> <p>If they require multidisciplinary care some treatment of the key MSA symptoms is done in other clinics (genetic testing, genetic testing, nutritional, physiotherapy, respiratory, ...).</p>	<p>There are no effective neurological disease-modifying therapies available yet, so treatment is focused on management of symptoms.</p> <p>The multiplicity of MSA symptoms requires the cooperation of different clinics.</p> <p>A patient with MSA in the initial phase of the disease does not necessarily have to be hospitalized in a neurological clinic for a long time.</p> <p>In the second phase of MSA disease development, the frequency of medical actions of individual symptoms at various times increases (insomnia, breathing, cough, constipation, urinary incontinence, gait, swallowing, vision, bowel and sexual function).</p> <p>In the third terminal phase locally already irreversible, dependent on support technology a patient with MSA can stay in a specialized long-term hospital, usually for a short time, or (b) continue in home care with adequate support for the underlying pathology (swallowing, ventilation, cardiac, nutritional support, ...).</p>	<p>Referral to national expert centres with involvement of multi-disciplinary teams in view of the rare disease.</p>



# PATIENT JOURNEY

## Multiple System Atrophy (MSA)

different needs  
at different times



Was this patient journey helpful?  
Help us improve patient care  
and participate in our short survey!



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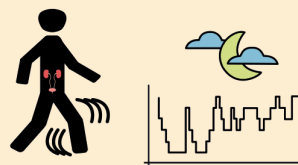



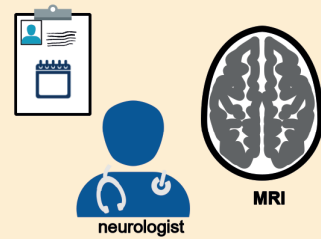

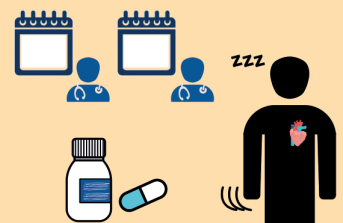
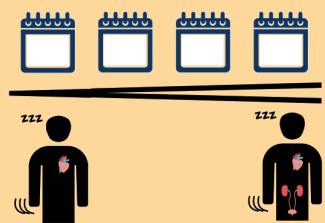




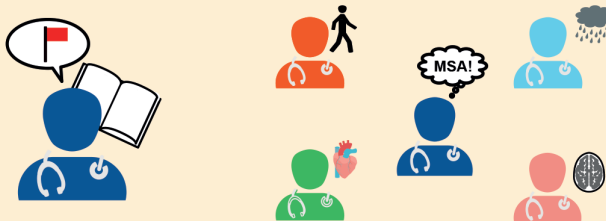
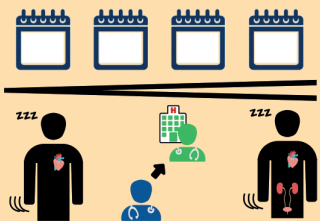
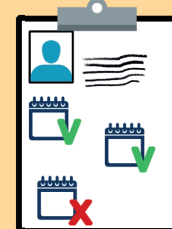


European  
Reference  
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for rare or low prevalence  
complex diseases

Network  
Neurological Diseases  
(ERN-RND)

Czech Association of  
**Atypical  
Parkinsonian  
Syndromes**

	First symptoms	Diagnosis	Treatment	Monitoring
Disease	<div></div> <p>Average age of onset 50-60+</p> <p>Autonomic disorder, movement symptoms, sexual dysfunction and REM-sleep behaviour disorder</p>	<div></div> <p>MSA with Parkinson (slowness, tremor) or MSA with Cerebellar (balance, speech).</p>	<div></div> <p>Only symptom treating (breathing, blood pressure control, incontinence, psychological support, palliative care).</p>	<div></div> <p>Monitored by expert centres with multidisciplinary teams.</p>
Clinic	<div></div> <p>neurologist</p> <p>Extensive neurological examination, blood pressure, genitourinary assessment, brain MRI).</p>	<div></div> <p>MSA can mimic other conditions such as PD and ataxia. It can take time to diagnose MSA.</p>	<div></div> <p>Identify symptoms, initiate regular treatment and referrals.</p>	<div></div> <p>Identify and monitor progression of symptoms. Integration with appropriate services.</p>
Challenges	<div></div> <p>First symptoms can be general or non-specific and may not be recognized by clinicians.</p>	<div></div> <p>Missed diagnosis: dangers of serious falls, respiratory symptoms, malnutrition, infections.</p>	<div></div> <p>Need for research to find a cure.</p>	<div></div> <p>Holistic care includes home care aspects and emotional support for patients and carers.</p>
Goals	<div></div> <p>Observation for "red flags". Greater awareness on MSA, its symptoms, psychological and emotional needs of patients, physical therapy needed</p>	<div></div> <p>Multi-disciplinary cooperation on developing new therapies and care pathways.</p>	<div></div> <p>Person with MSA has a care plan that includes wishes for future care and interventions.</p>	

**MRI** Magnetic Resonance Imaging  
**MSA** Multiple System Atrophy  
**O<sub>2</sub>** Oxygen  
**PD** Parkinson's Disease  
**REM** Rapid Eye Movement

Please note that specific terms (e.g. home care services, general physician, physiotherapy) do not include the same services in all EU countries and might differ from country to country. Patient advocacy groups can often provide support and resources for patients and families.

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**European Reference Network**  
 for rare or low prevalence complex diseases  
 **Network**  
 Neurological Diseases (ERN-RND)


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