

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.

PATIENT JOURNEY

Multiple System Atrophy (MSA)

different needs
at different times

Overview	1 - First symptoms	2 - Diagnosis	3 - Treatment	4 - Monitoring
<p>Disease</p> <p>Presentation after the age of 50 years, average age of onset between 50-55 years. For the first time in ~16 years, MSA is a multiple disease with 4 key symptoms.</p> <p>First initial symptoms are subtle and non-specific.</p> <p>Symptoms fall in four categories:</p> <ul style="list-style-type: none"> motor symptoms - include unsteady gait and difficulties standing, balance problems, slowness of movement, freezing and falls, irregular tremor of the limbs. Parkinsonian symptoms are possibly responsible for the tremor. autonomic nervous system symptoms - which are involuntary processes, e.g. heart rate, blood pressure, coughing, urticaria, sexual and bowel function. <p>Additionally, other symptoms may include uncontrollable laughing or crying (called emotional lability), vivid dreams, memory loss during the day, excessive sweating of night, constipation/diarrhea, weight gain, and 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"> MSA with Parkinsonian MSA where slowness of movement, rigidity and bradykinesia of movement, slightly and better pronounced than motor movements and speech are affected. MSA with cerebellar MSA-C where issues with balance, fine motor movements and speech are affected. <p>Different levels of diagnostic certainty were defined in the latest international diagnostic criteria:</p> <ul style="list-style-type: none"> Clinically established MSA Probably established MSA Probable MSA, this is a research only category and has been designed to be applied with early signs of MSA and can be considered for clinical trials. <p>Additional diagnosis of MSA is only possible from examining the brain cells from different parts of the brain (see introduction).</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>In the selection of neuro-symptoms to most effectively address the neurological clinic:</p> <ul style="list-style-type: none"> Along disorders They require multidisciplinary care since some treatment of these key MSA symptoms is done in other 	<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 may 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 advice of medical specialist symptoms of various clinical domains (respiratory breathing, cough, constipation, bone loss, depression, general nutritional, PEG, physiotherapy...)</p> <p>In the third terminal phase (usually already irreversible, dependent on support technology) a patient with MSA can stay at home until the end of their life, usually for a short time, or</p> <ul style="list-style-type: none"> It is recommended that care paths anticipate support for palliative care, palliative care, cardiac, nutritional support, PEG. 	<p>Referral to national expert centre with involvement of multi-disciplinary teams in case of this rare disease.</p>	



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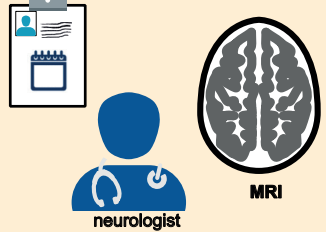

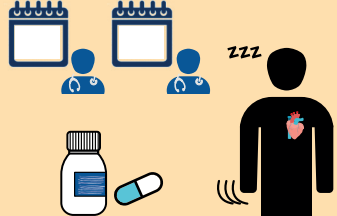
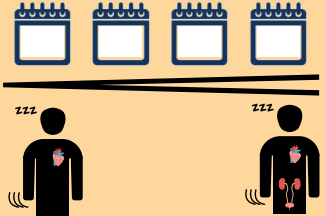



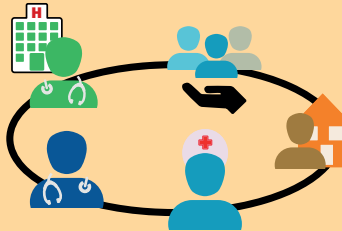
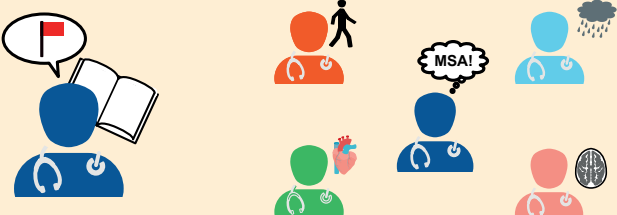

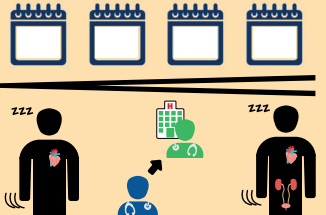
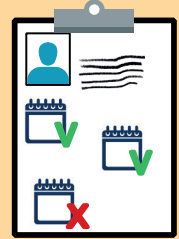


European
Reference
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for rare or low prevalence
complex diseases

Network
Neurological Diseases
(ERN-RND)

Czech Association of
**Atypical
Parkinsonian
Syndromes**

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

- GP** General Practitioner
- MRI** Magnetic Resonance Imaging
- MSA** Multiple System Atrophy
- O₂** 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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