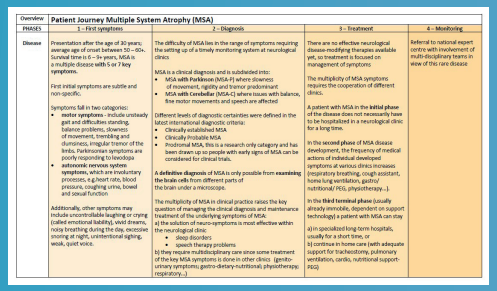
Patient Journeys are **info-graphical overviews** that visualize patients' needs in the care of their rare disease.

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)			
PHASES	1 – First symptoms	2 – Diagnosis	3 – Treatment	4 – Monitoring
Disease	Presentation after the age of 30 years; average age of onset between 50 – 60+. Survival time is 6 – 9+ years, MSA is a multiple disease with 5 or 7 key symptoms. First initial symptoms are subtle and non-specific. Symptoms fall in two categories: • **motor symptoms** – include unsteady gait and difficulties standing, balance problems, slowness of movement, trembling and clumsiness, irregular tremor of the limbs. Parkinsonian symptoms are poorly responding to levodopa • **autonomic nervous system symptoms**, which are involuntary processes, e.g heart rate, blood pressure, coughing urine, bowel and sexual function Additionally, other symptoms may include uncontrollable laughing or crying (called emotional liability), vivid dreams, noisy breathing during the day, excessive snoring at night, unintentional sighing, weak, quiet voice.	The difficulty of MSA lies in the range of symptoms requiring the setting up of a timely monitoring system at neurological clinics MSA is a clinical diagnosis and is subdivided into: • MSA **with Parkinson** (MSA-P) where slowness of movement, rigidity and tremor predominant • MSA **with Cerebellar** (MSA-C) where issues with balance, fine motor movements and speech are affected Different levels of diagnostic certainties were defined in the latest international diagnostic criteria: • Clinically established MSA • Clinically Probable MSA • Prodromal MSA, this is a research only category and has been drawn up so people with early signs of MSA can be considered for clinical trials. A **definitive diagnosis** of MSA is only possible from **examining the brain cells** from different parts of the brain under a microscope. 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: a) the solution of neuro-symptoms is most effective within the neurological clinic • sleep disorders • speech therapy problems b) they require multidisciplinary care since some treatment of the key MSA symptoms is done in other clinics (genito-urinary symptoms; gastro-dietary-nutritional; physiotherapy; respiratory...)	There are no effective neurological disease-modifying therapies available yet, so treatment is focused on management of symptoms The multiplicity of MSA symptoms requires the cooperation of different clinics. 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. In the **second phase** of MSA disease development, the frequency of medical actions of individual developed symptoms at various clinics increases (respiratory breathing, cough assistant, home lung ventilation, gastro/ nutritional/ PEG, physiotherapy...). In the **third terminal phase** (usually already immobile, dependent on support technology) a patient with MSA can stay a) in specialized long-term hospitals, usually for a short time, or b) continue in home care (with adequate support for tracheostomy, pulmonary ventilation, cardio, nutritional support-PEG)	Referral to national expert centre with involvement of multi-disciplinary teams in view of this rare disease

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

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PATIENT JOURNEY

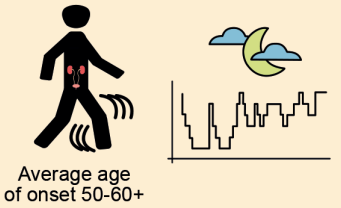
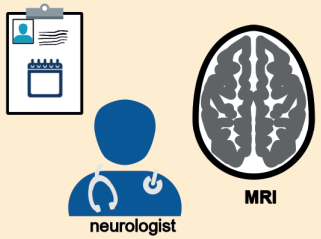
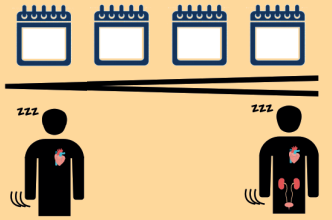
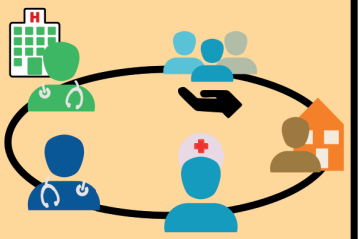
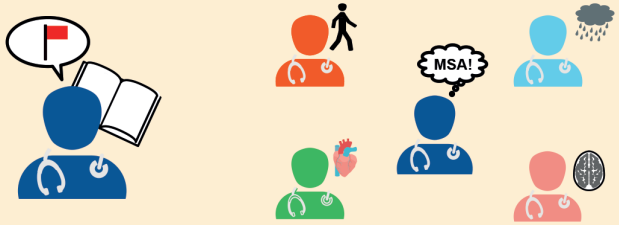
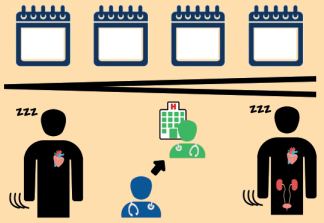
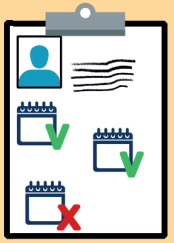
Multiple System Atrophy (MSA)

different needs
at different times

European Reference Network
for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

Czech Association of
Atypical Parkinsonian Syndromes

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

MRI	Magnetic Resonance Imaging
MSA	Multiple System Atrophy
O_2	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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