

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.

Multiple System Atrophy (MSA)

The patient journey



A visual description of what patients need and how clinicians can address them



For a digital version of the patient journey scan the QR code or visit the ERN-RND website:

<https://www.ern-rnd.eu/patient-journey-multiple-system-atrophy-msa/>





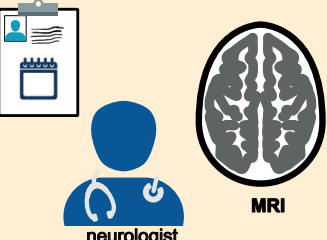
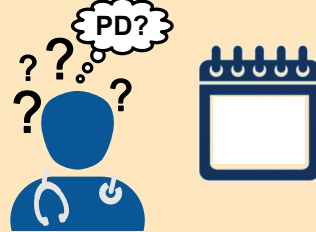
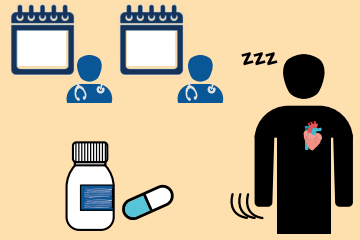
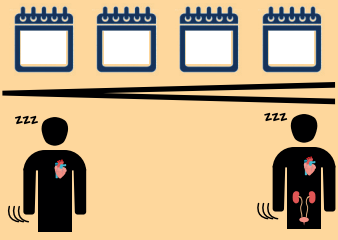

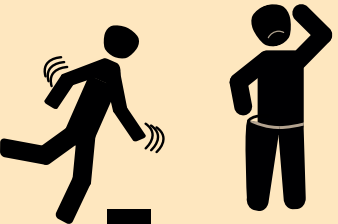

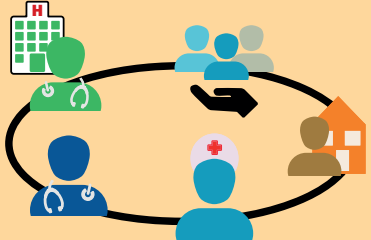
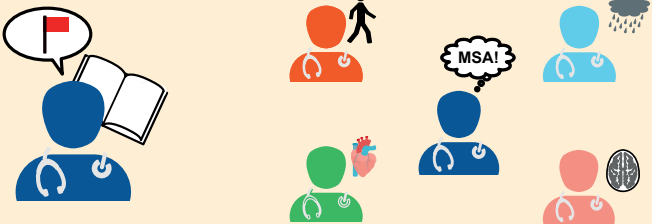

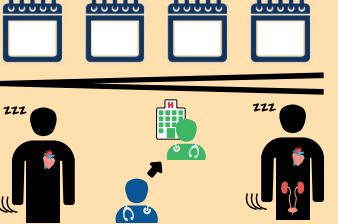
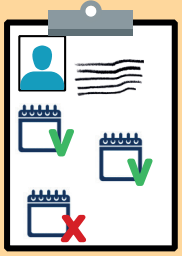


**European
Reference
Network**

for rare or low prevalence
complex diseases

 **Network**
Neurological Diseases
(ERN-RND)

**Czech Association
of Atypical
Parkinsonian Syndromes**

	First symptoms	Diagnosis	Treatment	Monitoring
Disease	 <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>neurologist</p> <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>Missed diagnosis: 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>Person with MSA has a care plan that includes wishes for future care and interventions</p>