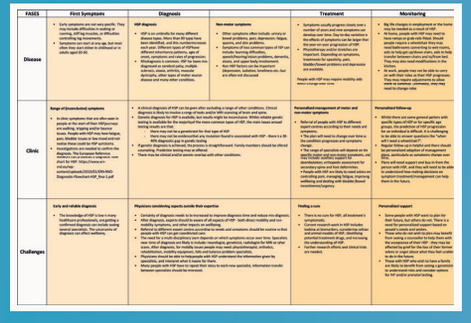
Patient Journeys are **info-graphical overviews** that visualize patients' needs in the care of their rare disease.

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

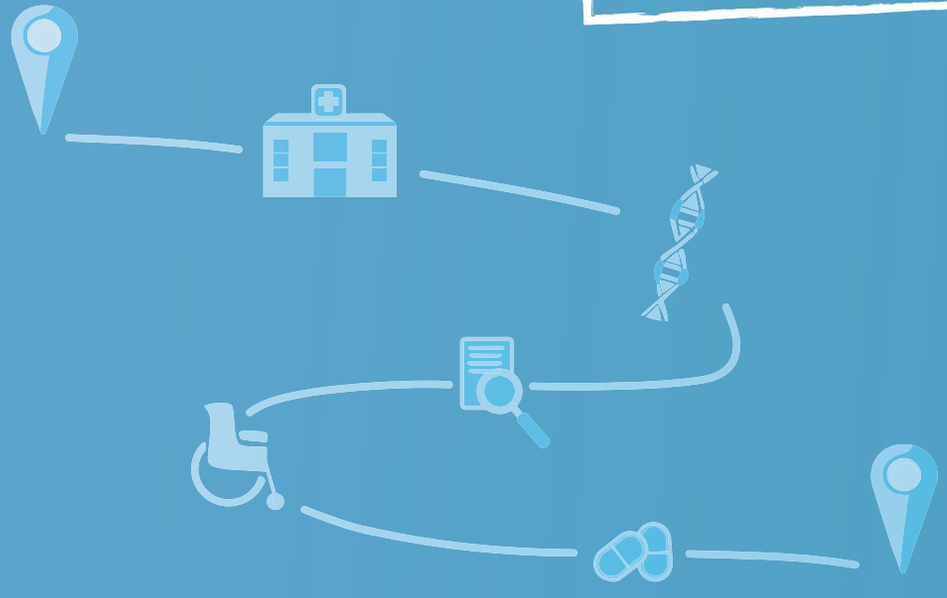
Downlaod this patient journey on our website.



PATIENT JOURNEY

Hereditary Spastic Paraplegias (HSPs)

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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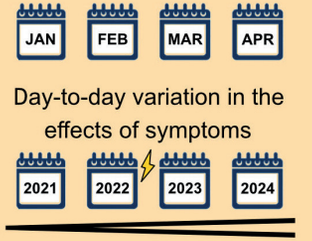
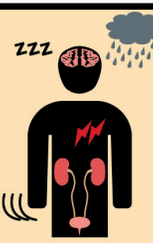
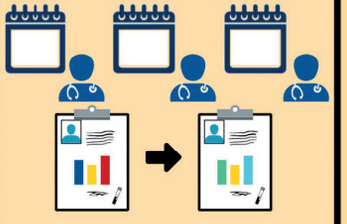
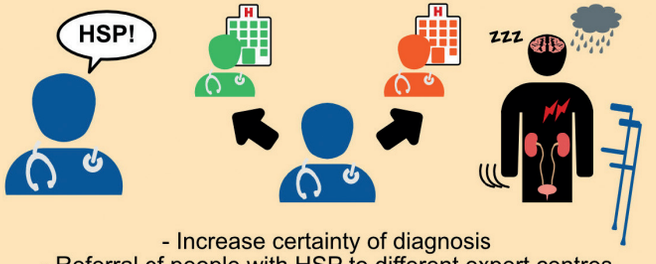
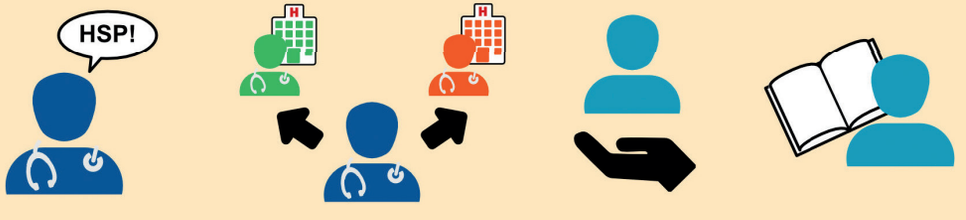
European Reference Network
for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

Euro-HSP
Federation of European HSP Associations

Hereditary Spastic Paraplegia
Taking Steps Toward a Cure

	First symptoms	Diagnosis		Treatment	Monitoring
Disease	 Early symptoms are often unspecific	 90+ different disease types. Misdiagnosis is common		 Day-to-day variation in the effects of symptoms Slow progression of symptoms. New symptoms can develop	 Understand how to accept life with HSP
			 Possible symptoms: fatigue, urinary issues, pain, depression, spasms, cognitive problems		
Clinic	 Early symptoms in people with HSP can include balance issues and tripping	 Clinical diagnosis after excluding other conditions		 Regular follow-up. Personlized plan changes over time with progression	 Plan to consider: future generations; changes at work; modifications at home
			 Genetic diagnosis might be inconclusive		
Challenges	 Knowledge of HSP is low in many healthcare professionals	 - Increase certainty of diagnosis - Referral of people with HSP to different expert centres - Awareness and prediction of all HSP-aspects		 No cure for HSP, only symptomatic treatment available. Research & clinical trials needed	 Not all people with HSP want to plan. Need for personalized support
Goals	 - Clinicians should be able diagnose HSP and know experts to refer people with HSP to - Support for people with HSP after diagnosis, including physiotherapy and stretching - Providing people with HSP with information and treatment options			 Get people with HSP to maintain a routine with physical activity. Best quality of life possible.	 Providing information about support networks; current research work; patient registries

HSP Heredetary Spastic Paraplegias

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.

Updated on November 2022.

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