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.

Downland this patient journey on our website.

EASES	First Symptom	Diamosis		Treatment	Monitoring
FASES			000000000000000000000000000000000000000		
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Was this patient journey helpful?

Help us improve patient care and participate in our short survey!



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PATIENT JOURNEY

Hereditary Spastic Paraplegias (HSPs)

different needs at different times





for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

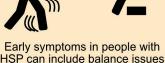


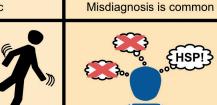


Disease

Challenges

Goals





Clinical diagnosis after excluding other conditions

HSP

90+ different disease types.



Possible symptoms: fatique,

Genetic diagnosis might be inconclusive



Treatment

Day-to-day variation in the effects of symptoms



Slow progression of symptoms New symptoms can develop



Monitoring

Understand how to accept life with HSP



Disclaimer

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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.





Regular follow-up. Personlized plan changes over time with progression



future generations; changes at work; modifications at home



Knowledge of HSP is low in many healthcare professionals



Diagnosis

- 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







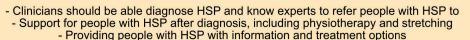


Get people with HSP to maintain a routine with physical activity. Best quality of life possible.



Providing information about support networks; current esearch work; patient registries







for rare or low prevalence complex diseases

Network Neurological Diseases (ERN-RND)

