

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.

For more information, please visit:
www.ern-rnd.eu/patient-journey-huntingtons-disease



HUNTINGTON DISEASE

The patient journey



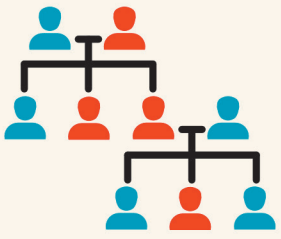









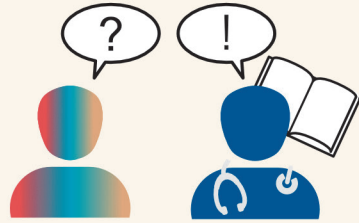


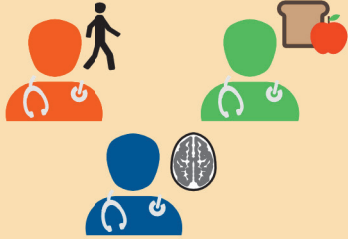
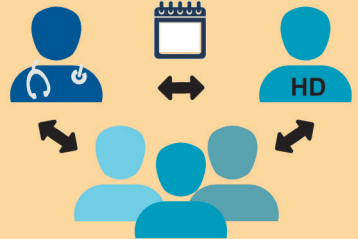
A visual description of what patients need and how clinicians can address them



European
Reference
Network

for rare or low prevalence
complex diseases

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

	Premanifest HD	First symptoms	Diagnosis	Treatment	Monitoring
Clinic	 <p>Most people with HD experience several close relatives developing HD</p>	 <p>Subtle and non-specific first symptoms fall in 3 categories: motor, cognitive, and behavioural</p>	 <p>Confirm clinical diagnosis with genetic testing. Genetic counselling is essential</p>	 <p>No disease modifying treatment. Symptoms managed and treated to maintain functionality and QoL</p>	 <p>Physical activity, psychological wellbeing and nutrition maintain function and autonomy</p>
Challenges	 <p>Fear of disease onset leads to ignoring symptoms</p>	 <p>Childhood Age > 30</p> <p>Differences in disease onset and first symptoms vary and lead to delay of diagnosis</p>	 <p>Symptom complexity leads to frequent misdiagnosis</p>	 <p>HD needs a multidisciplinary and holistic approach. A long-term perspective is essential</p>	 <p>Disease progression leads to struggle to adjust</p>
Goals	 <p>Educate clinicians about premanifest HD</p>	 <p>Educate families on how to best cope and seek support</p>	 <p>Accurate & quick diagnosis. Good follow-up process. Support network for patients</p>	 <p>Establish multidisciplinary teams</p>	 <p>Build trusting relationships between patients, families and clinicians</p>

