

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	
1. Purpose	Huntington's Disease (HD) is an autosomal dominant neurodegenerative disorder with a life expectancy of 15-20 years. It is caused by a mutation in the HTT gene. The disease is characterized by motor, cognitive and psychiatric symptoms. The purpose of this patient journey is to provide an overview of the patient's experience with HD and to identify the needs of patients and their families.
2. Scope	This patient journey covers the experience of patients and their families from the time of diagnosis to the end of life. It includes the physical, cognitive and psychiatric aspects of the disease, as well as the social and emotional impact on the patient and their family.
3. Objectives	The objectives of this patient journey are to: <ul style="list-style-type: none"> Identify the needs of patients and their families at different stages of the disease. Provide an overview of the patient's experience with HD. Identify the gaps in the current care of patients with HD. Provide recommendations for improving the care of patients with HD.
4. Challenges	The challenges of this patient journey are: <ul style="list-style-type: none"> The lack of a cure for HD. The progressive nature of the disease. The social and emotional impact on the patient and their family. The lack of support services for patients and their families.
5. Goals	The goals of this patient journey are: <ul style="list-style-type: none"> To provide an overview of the patient's experience with HD. To identify the needs of patients and their families at different stages of the disease. To provide recommendations for improving the care of patients with HD. To identify the gaps in the current care of patients with HD.



PATIENT JOURNEY

Huntington's Disease (HD)

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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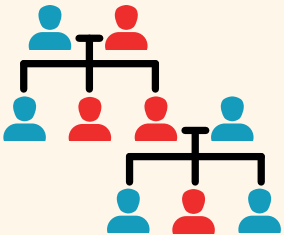

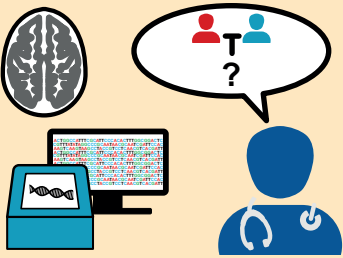
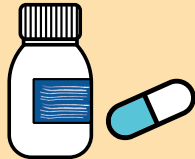
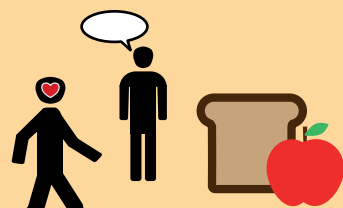



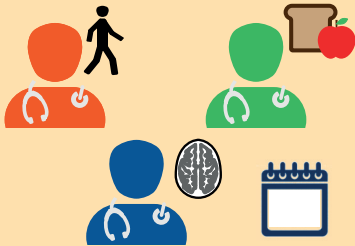
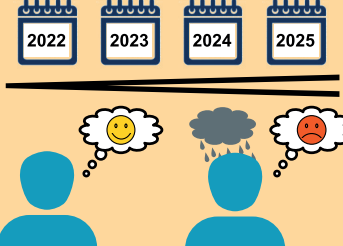
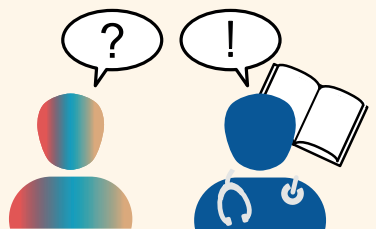






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	Premanifest HD	First Symptoms	Diagnosis	Treatment	Monitoring
Clinic	 <p>Most people with HD experience several close relatives developing HD.</p>	 <p>Subtle and non-specific first symptoms fall in 3 categories: motor, cognitive, and behavioural.</p>	 <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>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>



HD Huntington's Disease

QoL Quality of Life

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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