

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:
<https://www.ern-rnd.eu/patient-journey-cervical-dystonia/>



Cervical Dystonia

The patient journey



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

DYSTONIA
EUROPE



European
Reference
Network

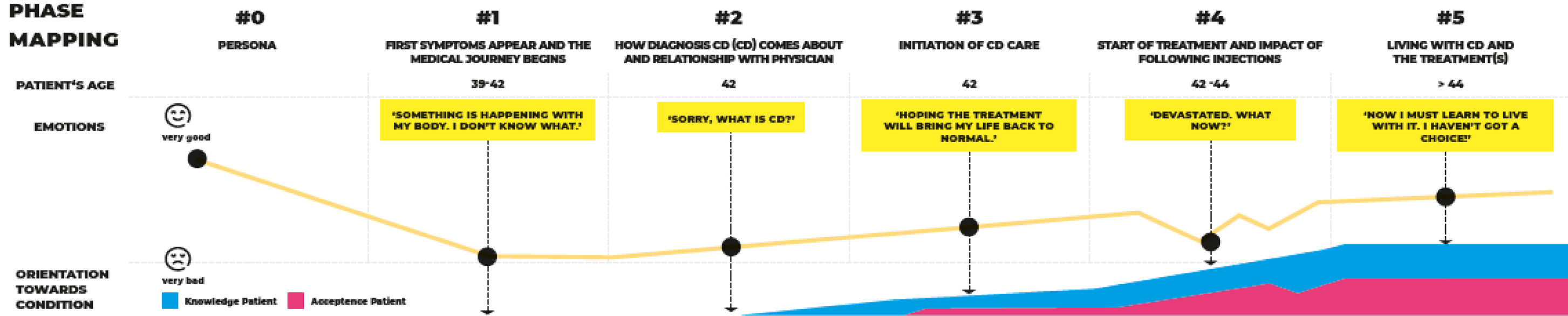
for rare or low prevalence
complex diseases

Network
Neurological Diseases
(ERN-RND)

 **IPSEN**
Innovation for patient care

GLOBAL
MEDICAL AFFAIRS

PHASE MAPPING



MOMENTS OF MEANING (QUOTES FROM THE PATIENT SURVEY)	#1	#2	#3	#4	#5	
	'I don't know what is happening with my body, and my husband and I are both anxious. I feel as if I am losing my identity and my spontaneity, and I'm afraid that my husband will stop loving me.'	'I did not feel understood, I felt it was all too fast, I did not feel supported by my neurologist and I did not feel reassured. I needed more time, more words to encourage me. The neurologist talked to me about the BoNT treatment but didn't mention anything about other complementary treatments.'	'Before starting the treatment, it would have helped me just to be told the truth by my neurologist, that the BoNT may help a lot, a little or not at all. And what further treatment might help.'	'When the following BoNT injections [after the 1st injection] did not work well, I lost all hope because I was told it was the only treatment option.' 'My neurologist may not be my BoNT injector and not know me as well as my neurologist. There is a lack of communication on how I am feeling and if my treatment is working effectively.'	'It's a daily journey, a daily fight, Dystonia is a part of me, but I'm not only a patient living with CD and I've learned to look at myself and the world around me differently.'	
MEDICAL EXPERIENCE	<p>Meet Lilly: 38 years old, before the onset of the disease</p> <p>Demographic data: 38 years old, teacher, middle income. Married to Ben, 45, employed electrician. 2 children, 5 and 7 years old. They live in a detached house in the suburbs of a larger European city.</p> <p>Psychography: financially responsible as she earns more than her husband. Lilly is always there for everyone. Her mother is still alive, her father recently died of cancer. She feels responsible for both her mother, who is living alone, and her mother-in-law, who suffers from the onset of dementia.</p> <p>Hobbies: jogging, reading, travelling, spending time with the family.</p> <p>Habits: busy social and working life, sleeps too little, eats mostly healthy food.</p> <p>Personal goals: time for family and travel, get out in nature more often, go horse riding.</p> <p>Social environment: good relationship with work colleagues and neighbours; she is liked by all.</p> <p>Wishes & needs: to live a self-determined life with her family for as long as possible.</p> <p>Digital habits: she chats with friends on WhatsApp, mostly sends photos of family and herself. She uses the internet mainly for her work as a teacher, to read the news and for online shopping.</p>	<p>FIRST SYMPTOMS</p> <p>She often uses her hand to keep her head still. When her stress level calms down a bit, the symptoms unfortunately do not disappear but intensify so that she can no longer go jogging and riding and is on sick leave for a few weeks.</p> <p>Multiple visits to her GP who prescribes strong pain killers and muscle relaxants, and refers her to different specialists.</p> <p>Most frequently suspected diagnoses: stress, psychological causes, herniated disc, tendonitis.</p>	<p>DIAGNOSIS OF CD</p> <p>Lilly's symptoms have worsened and she cannot keep her head still and straight. Her sleep quality is very poor, she is depressed and suffers from fatigue. Her GP finally refers her to a neurologist specialised in dystonia who diagnoses her with "CD". She does not receive clear information about the disease or support from the diagnosing neurologist. In an online article, she learns more about the disease and its treatment.</p>	<p>DISCUSSED TREATMENT OPTIONS WITH PHYSICIAN</p> <p>Lilly's neurologist refers her to a movement disorder clinic where it is recommended she get BoNT injections. The neurologist also suggests physiotherapy in addition to the injections but doesn't direct her to a physiotherapist who is knowledgeable about dystonia. He advises her to search for a physiotherapist in her area, one that ideally specialises in CD.</p> <p>She often struggles with fatigue which is caused both by the painkillers and by poor sleep quality. She hopes that the pain will get better with time.</p>	<p>START OF TREATMENT: BoNT injections</p> <p>In the beginning, the BoNT treatment provides Lilly with relief, but she experiences ups and downs. Lilly receives her BoNT injections every 3 months, but finds it particularly difficult in the days and weeks before her next scheduled injection. Nevertheless, the BoNT is the treatment with the greatest impact on her symptoms. On the advice of her physiotherapist, she applies to her health insurance company for an armchair with headrest to put her head on, and she gets this approved. After spending a considerable amount of time and effort on the paperwork, she finally gets disabled worker status. In phases when the BoNT is working well, she decides to try yoga and relaxation.</p>	<p>TREATMENT STRATEGY</p> <p>Lilly has often taken sick leave during bad phases. Lilly's treatment strategy is multidisciplinary: BoNT injected by an experienced neurologist, physiotherapy, acupuncture, painkiller gel application on the pain zones, sport (swimming, walking, cycling), healthy diet, benzodiazepines if needed and however, there is no central care coordinator and Lilly is often left to find allied healthcare professionals (e.g. physiotherapist) on her own.</p>
EMOTIONAL EXPERIENCE	<p>PATIENT</p> <p>Exhaustion, anxiety and uncertainty are combined over time with great frustration with her doctors and therapists who cannot find a cause for her symptoms.</p> <p>FAMILY/ENVIRONMENT</p> <p>Her partner is very supportive and understanding and takes over all the roles she feels she can't do. Her friends and colleagues cannot understand what she is suffering from and wonder if Lilly has Parkinson's disease. She feels as if nobody is able to help her.</p>	<p>PATIENT</p> <p>She is very relieved to finally have a diagnosis. At last, she knows that she is not crazy. At the same time, shortly after the diagnosis and the conversation with her neurologist, she can't really grasp what CD means for her life, because she doesn't know anything about it. Lilly is disappointed and sad that there is 'no real cure' and that the available options are drugs and neurotoxin, which only serve to treat the symptoms.</p> <p>FAMILY/ENVIRONMENT</p> <p>Lilly's family and friends are also relieved that the cause of her symptoms has been identified. They feel that Lilly doesn't like to speak about it and accept her as she is. When her colleagues learn that she suffers from CD, they empathise. But they don't really understand.</p>	<p>PATIENT</p> <p>Lilly hopes that the treatment will help her to return to a normal life. She is suffering from a high level of psychological stress and severe limitations in everyday life. She avoids socialising because she can't stand the glances of others.</p> <p>Sometimes she cries, feels angry, and has mood fluctuations, asking herself 'why me?'</p> <p>FAMILY/ENVIRONMENT</p> <p>Lilly is surrounded by her family, her friends, and her colleagues who show a lot of support and understanding. A good friend encourages her to contact a dystonia self-help group where she learns about the importance of psychotherapeutic support and receives the contact details of psychotherapists.</p>	<p>PATIENT</p> <p>After being frustrated at first, Lilly has learned to cope with the varying success of the treatment.</p> <p>If the BoNT injections do not work well, she rests more and avoids going to work and socialising. When the BoNT injections work well, she can return to an almost normal life. She has good phases and bad phases with anxiety and depression.</p> <p>FAMILY/ENVIRONMENT</p> <p>Her family, especially her children, give her support and strength not to lose her courage to face life. Her husband helps her a lot with the preparation of her application to get disabled worker status.</p>	<p>PATIENT</p> <p>Today, Lilly does not have the same job because she had to give up her position as head teacher. She has learned to live with her illness and has begun to accept it. Step by step, she is rebuilding her life again and realises that she can still socialise, do her hobbies and help other people.</p> <p>FAMILY/ENVIRONMENT</p> <p>All in all, her family and friends have found a good way to deal with the disease. Sometimes they have conflicts because Lilly's husband forgets she is tired and everyday activities take her longer. Sometimes he forgets that she is not the same person as before.</p>	



This work is generated within the European Reference Network for Rare Neurological Diseases - Project ID No

739510