

Rare forms of dementia, such as frontotemporal dementia, Lewy body dementia, or vascular dementia, remain poorly recognized – both in clinical practice and in public awareness. Their symptoms are often atypical, including behavioral changes, emotional disturbances, or motor difficulties. As a result, patients and their families often receive support too late, and care tends to be reactive. In contrast to Alzheimer's disease, these rare dementias remain on the margins of care systems and scientific research.

The **ENSURED** project (Empowering Needs-based Social Health and inclUsive care for RarEr Dementias) is an international research initiative aimed at improving the quality of life for people living with rare forms of dementia in moderate to advanced stages of the disease. It spans six European countries and brings together researchers, patient organizations, practitioners, people with dementia, and their caregivers. A key element is the participatory approach – people with lived experience co-develop tools and solutions.

The project will study so-called **care transition points** – moments when it becomes necessary to adjust the form of care to the changing needs of the person with dementia and their caregiver (e.g., a shift from home to institutional care, changes in caregiver roles, symptom deterioration). Qualitative research will be conducted with patients, their relatives, and professionals. Additionally, the team will compare systemic solutions across countries and organize international co-creation workshops to develop tools for adaptive care planning.

ENSURED addresses real-world challenges: the lack of diagnostic and educational tools tailored to rare dementias, limited long-term care resources, stigmatization of patients and caregivers, and the absence of clear support pathways. In response, a set of practical recommendations, interactive educational materials, and a toolkit for adaptive, personalized care will be developed.

The project will also create an updated version of the **INTENSE** educational simulation tool, which supports understanding the daily experiences of people with dementia. International co-creation workshops are planned for patients, caregivers, and professionals, along with reports and recommendations for health service designers that could have a meaningful impact on healthcare policy.

The ultimate goal of ENSURED is to create a **friendly, personalized, predictable, and flexible system of support** – one that is tailored not only to the progression of the disease but also to the emotional and social realities of people living with it. Thanks to this project, rare dementias may no longer be treated as exceptions, but rather as trailblazers for new standards of care – more empathetic, flexible, and grounded in real human needs. ENSURED will demonstrate that even in diagnostically and systemically challenging areas, effective solutions can be developed – provided they are co-created with the people directly affected.