

## Project partners

A multi-disciplinary consortium of eight partner institutions from six countries – France, Germany, the Netherlands, Portugal, Sweden and the United Kingdom are collaborating to improve care and support for people with dementia. The research teams represent academia and industry as well as a patient and carer advocacy organization.



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**RHAPSODY**  
 research and strategy for dementia in the young



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A joint European effort to improve care and support for people with young onset dementia

# RHAPSODY

## Research and strategy for dementia in the young

### YOUNG ONSET DEMENTIA

YOD IS DEFINED BY AN ONSET OF SYMPTOMS BEFORE THE AGE OF 65 YEARS

1 IN 1000 BETWEEN THE AGES OF 45 AND 65 YEARS IS AFFECTED BY YOD

#### Specific challenges

**For the families:** YOD leads to premature retirement and reduced family income. There are often children living within the households and for them it is hard to learn to handle their parent's illness. Compared to people with late-onset dementia, care may be required for a longer period of time and cost of illness is likely to be higher.

**Diagnosis:** Since it is uncommon for dementia to strike at such a young age, the road to diagnosis is challenging, requiring the involvement of specialists and costly examinations.

**Support and services:** Existing health and social care services for (older) people with dementia are mostly inappropriate for people with YOD. There's a lack of services that meet the specific needs of younger people with dementia and their families. Specific therapeutic programmes such as cognitive and physical training and behavioural management, are almost non-existent.

The main goal of RHAPSODY is to improve care for people with YOD by supporting their carers.

RHAPSODY has four major aims.

- 1 To evaluate the policy and information environment that provides the framework for the treatment and care of people with YOD and their carers in six European countries
- 2 To assess the specific and individual needs of this particular group
- 3 To use this information for designing an internet-based, multimedia, interactive learning course for carers of people with YOD
- 4 To test this learning course in a pilot study at three sites in France, Germany and the United Kingdom

**Impact:** The results of RHAPSODY will provide a basis for developing strategies to improve treatment and care for people with YOD, and support for their carers. RHAPSODY will deliver a model of a user-friendly, universally accessible and cost-effective type of healthcare intervention. The learning course will be made available to patient organizations across Europe to complement existing services. Selected modules of the learning course will be used in the training of healthcare professionals. Thus, RHAPSODY will contribute to increasing awareness and competence while reducing the stigma associated with YOD.

#### Work packages

The RHAPSODY work plan includes six work packages with specific tasks

- 1 **Coordination, monitoring and quality management of the whole project**
- 2 **Policy and information environment analysis**
  - To analyse and compare the health and social care policies in participating countries with regard to people with YOD and their carers
  - To review and compare the information for health care professionals as well as the information provided for people with YOD and their carers by national organisations
- 3 **Needs assessment**
  - To identify the needs of people with YOD and their carers at different stages of the disease
  - To explore differences in experiences, needs and access to services across six European countries
- 4 **Intervention design and product development**
  - To design an intervention for carers according to the identified healthcare policies, strategies and needs of people with YOD
  - To provide an internet-based, interactive convenient learning course format of delivery
- 5 **Pilot Study**
  - To evaluate the learning course in a pilot study with regard to feasibility, acceptance and user satisfaction
  - To compare and evaluate different outcome measures and to estimate effect sizes
- 6 **Dissemination, implementation and exploitation**
  - To communicate emerging scientific findings of the project
  - To develop a comprehensive dissemination and sustainability strategy