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The development of an online information and support program for informal carers of people living with YOD: The Rhapsody study

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RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young) is an EU Joint Programme - Neurodegenerative Disease Research (JPND) initiative that aims to improve information and support for families living with young onset dementia (YOD). Defined by symptom presentation before the age of 65 years, YOD is relatively rare and associated with diagnosis difficulties. Extensive family impact includes carer burden and stress, relationship disruptions and financial decline, all of which are exacerbated by a lack of age-appropriate services, support and information. This multi-disciplinary collaboration across six European countries developed an internet-based e-learning program for families living with YOD. Information and policies related to YOD were analysed from on-line reviews completed in all countries. Carer perspectives on needs and experiences were explored using in-depth interviews in the Netherlands, followed by focus groups in England, France, Germany, Portugal and Sweden. An intervention based on an on-line support program was considered appropriate due to relatively low prevalence of YOD, geographical spread and mobility restrictions resulting from the condition. Findings from early research stages informed the design and content of the 7-Part program, which explained clinical background, psychosocial perspectives, family issues, legal aspects and the importance of carer support. Produced in English, German and French, the intervention was tested by volunteer family carers in England, Germany and France.

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