

End-of-life care in institutionalized people with Young Onset Dementia (YOD): the Care4Youngdem-study

<https://neurodegenerationresearch.eu/survey/end-of-life-care-in-institutionalized-people-with-young-onset-dementia-yod-the-care4youngdem-study/>

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Netherlands

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End-of-life care in institutionalized people with Young Onset Dementia (YOD): the Care4Youngdem-study

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ZonMw

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The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Research Abstract

Young-onset dementia (YOD) refers to the onset of dementia before the age of 65. As dementia progresses the risk of institutionalization of People with YOD (PwYOD) increases. Although

literature about institutionalization rates in YOD is scarce, our NEEDs in Young-onset Dementia (NEEDYD)-study showed that 33% of the patients was institutionalized after two year follow-up. Studies on characteristics of institutionalized PwYOD are largely lacking. Our Dutch Behavior and Evolution in Young Onset Dementia (BEYOND)-study is the only study that assessed institutionalized people with YOD, but did not have the aim to map end-of-life care.

We propose a study in which we map the practice of palliative care in PwYOD from the views of Elderly Care Physicians (ECPs) and PwYOD and their family members and to provide YOD specific recommendations on palliative care. This Care4Youngdem-study partly replicates The Dutch End-of-Life in Dementia (DEOLD)-study. The DEOLD study is a large national cohort-study of the course and care-related aspects of institutionalized people with LOD. ECPs and family-members completed questionnaires covering a broad area of care-aspects with special emphasis on palliative care.

The Care4Youngdem-study is a mixed-method study and consists of three parts:

1. a. Questionnaire based survey among ECPs who care for people with YOD on palliative care practices at baseline and within two weeks after death of institutionalized people with YOD.
b. Questionnaire based survey among family members on palliative care practices at baseline and within two months after death of institutionalized people with YOD.
2. a. Focusgroup interviews with ECPs treating institutionalized people with YOD.
b. Focusgroup interviews with community dwelling people with YOD and with family-members (partner, children, parents) about views regarding palliative care.
3. Delphi consensus procedure in order to formulate YOD specific, recommendations for the white paper based on the outcomes of part 1 and 2.

Lay Summary

Further information available at:

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Investments > €500k

Member States:

Netherlands

Diseases:

Alzheimer's disease & other dementias

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