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J Pain Symptom Manage. 2014 Apr;47(4):710-20. doi: 10.1016/j.jpainsymman.2013.05.015. Epub 2013 Jun 5.



## Dying with dementia: symptoms, treatment, and quality of life in the last week of life.

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### Abstract

**CONTEXT:** Burdensome symptoms present frequently in dementia at the end of life, but we know little about the symptom control provided, such as type and dosage of medication.

**OBJECTIVES:** To investigate symptom prevalence and prescribed treatment, explore associations with quality of life (QOL) in the last week of life, and examine symptom prevalence by cause of death of nursing home residents with dementia.

**METHODS:** Within two weeks after death, physicians completed questionnaires about symptoms and treatment in the last week for 330 nursing home residents with dementia in the Dutch End of Life in Dementia study (2007-2011). We used linear regression to assess associations with QOL, measured by the Quality of Life in Late-Stage Dementia scale. Causes of death were abstracted from death certificates.

**RESULTS:** Pain was the most common symptom (52%), followed by agitation (35%) and shortness of breath (35%). Pain and shortness of breath were mostly treated with opioids and agitation mainly with anxiolytics. At the day of death, 77% received opioids, with a median of 90 mg/24 hours (oral equivalents), and 21% received palliative sedation. Pain and agitation were associated with a lower QOL. Death from respiratory infection was associated with the largest symptom burden.

**CONCLUSION:** Symptoms are common in dementia at the end of life, despite the large majority of residents receiving opioids. Dosages may be suboptimal with regard to weighing of effects and side effects. Future research may employ observation on a day-to-day basis to better assess effectiveness of symptom control and possible side effects.

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**KEYWORDS:** Dementia; end-of-life care; opioids; palliative care; palliative sedation; symptom control; symptoms; treatment

PMID: 23916680 DOI: [10.1016/j.jpainsymman.2013.05.015](https://doi.org/10.1016/j.jpainsymman.2013.05.015)

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