



Exploring advanced dementia in Scotland's care homes: prevalence and understanding

Dr Jenni Burton

NES/CSO Postdoctoral Clinical Lecturer and Honorary Specialist Registrar in Geriatric Medicine,
University of Glasgow & NHS Lanarkshire

We do not know how many people are living in Scotland's care homes with advanced dementia. This lack of data has significant consequences for those individuals, their families and the professionals who care for them. This research has sought to address this gap by surveying care home staff and exploring professional perspectives on how to improve care and support for those affected by advanced dementia.

Two pieces of academic research were undertaken to address this challenge:

1. To estimate the prevalence of people currently living with advanced dementia in Scotland's care homes from the perspective of care home practitioners – using a short online survey.
2. To explore understanding of the term 'advanced dementia' and how this is recognised and supported in the care home setting – through semi-structured qualitative interviews involving care home professionals.

What we did

A national survey of adult care home services in Scotland was undertaken over a 12-week period from January to April 2025. In addition, a further 20 in-depth follow-up interviews were conducted with a smaller sample of participants to provide additional insights and shape recommendations.

This research was commissioned by Alzheimer Scotland and conducted independently at the University of Glasgow. Dissemination and participation were supported by Scottish Care, ENRICH Scotland and existing professional networks.

This is a definition of 'advanced dementia' used in the UK:

Triggers that indicate someone is entering a later stage are:

- Unable to recognise family members or consistently unable to have meaningful conversations
- Completely dependent on others for care or unable to do activities of daily living
- Recurrent episodes of delirium
- Aspiration pneumonia
- Urinary and faecal incontinence

Plus any of the following:

- Weight loss
- Urinary tract infection
- Skin failure or stage 3 or 4 pressure ulcers
- Recurrent fever
- Reduced oral intake

Adapted from Gold Standards Framework Proactive Identification Guidance (7th edition, 2022)[14]

What we found

Survey responses were received from care home services in all **14** territorial NHS Health board areas and all **32** local authority areas.



Responses were received from **218** care home services, a completion rate of **21.9%** across all adult care home services.



If focusing solely on older peoples' care homes, the **210 responses** from these services account for a completion rate of **27.6%**.



Three-fifths (**61.5%**) of care homes are supporting people living with dementia who do not have a diagnosis.



The definition of advanced dementia was generally acceptable to care home staff. Some indicated it could include symptoms of stress and distress.



Concerns were raised about the suitability of the current model of funding to support the needs of people living with advanced dementia.



Average prevalence of advanced dementia among survey respondents was **40.6%** (*all adult care home services*) and **41.6%** (*older peoples' services only*).



We estimate **14,826** people residing in older peoples' care homes in Scotland are living with advanced dementia.



Recommendations

- Everyone living in a care home with dementia must have equitable access to a diagnosis and appropriate post diagnostic support tailored to their needs and those of their caregivers.
- There is an urgent need for transparency around how nursing care needs are assessed and for consistency across Health and Social Care Partnerships in decision-making and resource allocation – with the lack of progress on a National Care Service and current financial context, this is a priority for action.
- Providing effective care, sensitive to the individual nature of peoples' journey living with dementia requires skilled and specialist expertise. This must be recognised and resources to support in-person training must be provided.
- We need to better understand the external healthcare support care homes require to support people living with advanced dementia and explore the barriers and facilitators of the varied service models operating across Scotland to ensure equitable access.