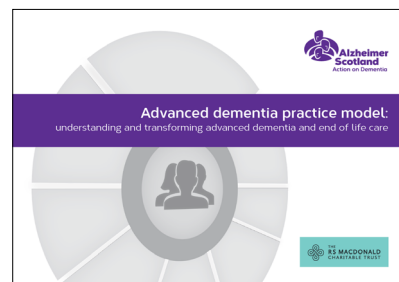


Alzheimer Scotland and Advanced Dementia

Alzheimer Scotland works to understand the needs of people with advanced dementia through research, consultation and direct engagement with people with lived experience. We have been instrumental in informing and influencing national dementia strategies and frameworks, ensuring that policies reflect real-life experiences and meet actual needs. As advocates for human rights-based care, we are focused on finding solutions that support dignity, autonomy and equality to improve services and support across health and social care for people in the later stages of their condition.

Advanced Dementia Practice Model (2015)

Building on Alzheimer Scotland's 5 Pillars Model of Post-Diagnostic Support and 8 Pillars Model of Integrated Community Support, the Advanced Dementia Practice Model was developed to provide a comprehensive care pathway from diagnosis to the end of life. The model aims to support people living with advanced dementia by setting out an evidence-based framework for delivering integrated, multi-disciplinary, specialist care to people with advanced dementia. The approach focuses on proactive, personalised interventions and ensuring continuity of care and support to meet the numerous and complex needs of people with advanced dementia, including medical and health needs and palliative and end-of-life care.



This model highlights the importance of:

- Integration across health and social care services to provide seamless support throughout the entire experience of living with advanced dementia
- Accessible, equitable service provision to deliver consistent standards of care and support
- A well-trained, skilled and knowledgeable workforce to manage complex needs present in advanced dementia

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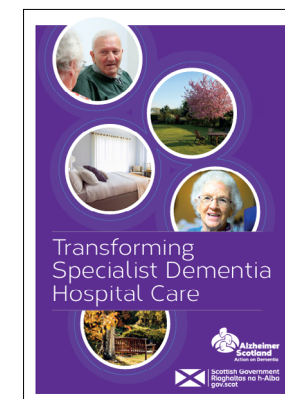
Transforming Specialist Dementia Hospital Care (2018)

Specialist dementia hospital care is required for people with dementia who have an acute psychological presentation due to dementia or a co-morbid mental health condition, but it is recognised that they will also have additional physical, emotional and social care needs. This report sets out a reimagined model of specialist hospital care for people with advancing dementia who have intensive and complex clinical care needs that require high level expert care. Focusing on rights-based care, it also provides an approach to build community capacity to enable the safe, supported transition of those who do not have a clinical need to remain in specialist hospitals and can be cared for in more homely settings in the community.

This report clearly sets out:

- A blueprint for service redesign with a focus on enhanced care quality, therapeutic approaches and person-centred practice
- An upskilled, multi-disciplinary workforce within an integrated care system is necessary to meet the complex needs of people with advanced dementia

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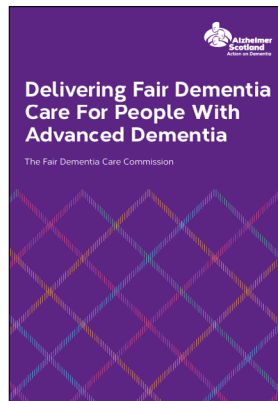
Delivering Fair Dementia Care for People with Advanced Dementia (2019)

The Fair Dementia Care Commission highlighted a profound inequality: people living with advanced dementia in care home settings face an unfair financial burden to meet the cost of their care. While people with advanced dementia require complex nursing and health care, they are required to pay a significant contribution towards the cost of their care, while similar care for other terminal illnesses is free within the NHS in Scotland. The needs of people with advanced dementia are still widely met by social care systems with no mechanism for continuing NHS care in non-hospital settings.

The Commission identified that:

- People with advanced dementia need fair and equitable access to appropriate health and nursing care, which is free at the point of delivery
- People need access to a mechanism that supports them to access health and nursing care when their condition progresses

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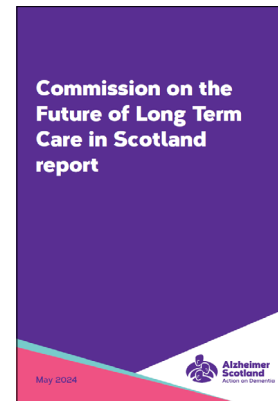
Commission on the Future of Long Term Care in Scotland Report (2024)

The Commission on the Future of Long Term Care in Scotland found that Scotland lacks a clear, co-ordinated national strategy for the provision of long term care, and currently relies on fragmented, market-driven systems and outdated models of care. It identified major issues including financial inequity for people with advanced dementia, limited care options, workforce challenges and challenges related to funding and paying for care. The report sets out 16 recommendations which provide a roadmap to reform long term care – not just in funding and resources, but in rethinking how Scotland plans, commissions and delivers long-term care in an ethical, equitable way.

The Commission's report highlights:

- A strategic, national and local plan for long term care provision is necessary to deliver care that meets the needs of people with advancing dementia
- Alternative models of care need to be considered to reflect the will and preferences of people who need long term care and support
- More needs to be done to acknowledge and address the challenge of meeting the cost of care

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Exploring Advanced Dementia in Scotland's Care Homes: Understanding and Prevalence (2025)

In recognition of the lack of data available to inform strategic planning for the provision of care, funding and resources, Alzheimer Scotland

commissioned research to better understand the prevalence of advanced dementia in Scotland's care homes. The research indicates that the scale of advanced dementia is substantial, with just under 15,000 care home residents affected by the condition. Significantly, it has also highlighted concerns around access to diagnosis in care home settings and the sustainability of the current funding model for nursing care.

The research has affirmed that:

- Everyone living in a care home with dementia must have fair and equitable access to a diagnosis, followed by appropriate post diagnostic support tailored to meet their needs
- There is an urgent need for transparency around how nursing care needs are assessed, and resources are allocated to meet those needs
- Providing effective care and support, sensitive to the individual nature of peoples' experiences of living with dementia, requires skilled and specialist expertise from trained practitioners

