Low expectations
Attitudes on choice, care and community for people with dementia in care homes

Executive summary
This booklet contains the executive summary and Appendix B of the Alzheimer’s Society report *Low expectations: Attitudes on choice, care and community for people with dementia in care homes.*

The full report can be read online at [alzheimers.org.uk/lowexpectations](http://alzheimers.org.uk/lowexpectations)

**Publication date**
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**Target audience**
This report is intended for a range of audiences including central and devolved government, policy makers, health and social care commissioners, and health and care providers. Its recommendations are intended to raise awareness, inform policy and change practice.

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The Society would especially like to thank the members of our expert stakeholder group, who helped to inform and steer this report. Particular thanks go to those peer reviewers of our report: Professor Graham Stokes, Director of Dementia Care at Bupa Care Services; Martin Green OBE, Chief Executive of the English Community Care Association; and Karen Culshaw, Regulatory Policy Manager at the Care Quality Commission.

In addition to surveys of people affected by dementia and care staff, Alzheimer’s Society commissioned YouGov Plc to survey the general public. These figures are cited as such. The total sample size was 2,060 adults.

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Executive summary

Analysis of recent studies suggests that in excess of 80% of residents living in care homes have dementia or significant memory problems. Providing care to people with dementia must be the primary concern and focus of the care home sector.

Across all those responding to our surveys, there were low expectations about the quality of life of people with dementia in care homes. More needs to be done to raise expectations about quality of life in care homes. Of UK adults responding to our YouGov poll, 70% said they would feel scared about moving into a care home in the future. Only 41% of family members responding to our survey thought the quality of life of the person with dementia was good, with over a quarter (28%) saying it was poor.

Views on the quality of care for people with dementia living in care homes were more positive, but the financial pressure on the care sector raises concerns about ongoing investment in training. Sector-led and government-supported improvement should be encouraged to ensure that standards improve. Of family members responding to our survey, 74% would recommend the care home to others, and 68% said the quality of care for the person with dementia was good. However, family members’ views on opportunities for activities were less positive, with only 44% of family members saying opportunities were good. 88% of care home staff responding said the dignity and respect people with which dementia in their care home were treated was good.

The process of finding information on care homes can be challenging, and family members and people with dementia need to be supported with information to enable them to assess quality of homes. Nearly a quarter (24%) of family members responding to our survey said that they found it difficult to find information on care homes. Respondents most frequently sought information directly from care homes themselves.

A significant number of people with dementia had moved care home since first going into care. Emphasis needs to be placed on seeing admissions to care homes as steps in a continuum of care, rather than steps into residences of last resort. Nearly a third (32%) of family members responding reported that the person with dementia had moved since first going into care, the most common reason being an increase in needs.

Experiences of support from health services and engagement with the community were mixed. Family members and staff responding were positive about how homes worked with doctors and family members. However, views on opportunities for trips out of the home, and how the home worked with volunteers, were less positive.
Low expectations

Methodology

This report presents new evidence about experiences of and views on people with dementia living in care homes. Evidence is drawn from surveys of family members of people with dementia (our DEMFAM survey), staff working in care homes (our DEMSTAF survey), and people with dementia themselves. These surveys were distributed to Alzheimer’s Society members, care homes in England, Wales and Northern Ireland, and through some Alzheimer’s Society staff and online.

The report also presents evidence from a YouGov poll carried out in December 2012, of 2,060 adults, into perceptions about care homes.

The report also draws on existing public policy evidence on care and performance of care homes.

Key findings

The key findings of the report are based on the findings from our surveys, research and YouGov poll of UK adults.

Context

- The UK has a large care home market and is likely to need significant numbers of care home places in coming years.
- Care home fees are paid through a mixture of state (mostly local authority) and private funding.
- It is widely accepted that the care system in the UK is underfunded and many family members and people with dementia have to pay large costs for care. The current financial and economic climate is a significant challenge to investment in high-quality care in care homes.
- Care homes are regulated according to compliance with standards, but concerns exist over the consistency of regulation and inspection and whether regulation by compliance can be effective in driving up quality of care.
- Improving care of people with dementia in care homes is recognised in various national strategies, and significant work is being undertaken across the sector to promote good care of people with dementia in care homes.

Choice

- 70% of UK adults responding to our YouGov poll said they would feel scared about moving into a care home in the future.
- Lack of support in the community and being unable to cope were the most common reasons for admission into care among DEMFAM respondents.
• Half (50%) of DEMFAM respondents said finding information on care homes had been easy, with 24% saying they found it difficult.

• Nearly a third (32%) of DEMFAM respondents said the person with dementia moved after going into care.

• DEMFAM respondents were most likely to access information on care homes from homes directly or from health and social care staff.

• More needs to be done to provide support for people with dementia in the community prior to their entering care.

• Local authorities, regulators and care homes themselves must support and promote choice and quality in care homes.

**Care**

This report provides a mixed picture about experiences of care of people with dementia in care homes.

• 74% of DEMFAM respondents said they would recommend the care home that the person with dementia was in to others, and 68% of DEMFAM respondents thought the quality of care received by the person with dementia in the care home was good.

• However, only 41% of DEMFAM respondents thought the quality of life of the person with dementia living in the care home was good.

• The wider public perception of quality of care in care homes appears lower than views expressed in DEMFAM, with only 30% of UK adults agreeing that people with dementia in care homes for older people were generally treated well.

• Staff and family members reported positive views on staff understanding and training. However, adherence to standards remains patchy, and staff responding to our DEMSTAF survey reported they want more training.

• Only 44% of DEMFAM respondents felt that opportunities for activities in the care home were good, suggesting that this is an area where further work is needed.

• Our YouGov survey found that UK adults generally do not feel that care homes are doing enough to prevent abuse in care homes, with 64% agreeing they were not doing enough. More than half (53%) of UK adults said the risk of a close relative being abused was the biggest concern they would have if the relative went into care.

• Continued efforts should be made to improve the quality of care and life of people with dementia in care homes, and the care home sector must do more to respond to the challenge of abuse in care homes.
4 Low expectations

Community

- Health services play a crucial role in ensuring that people with dementia can have a good quality of life in care homes, but challenges persist in access to and support from health services for this group. DEMFAM found that 56% of respondents said support from GPs was good, but views on other health services were less positive.

- Views on support from dentists were mixed, with only 23% of respondents saying access and support was good.

- DEMFAM found that only 26% of respondents said the care home was good on opportunities for trips out the home, and 31% said they were poor.

- Only 28% of DEMFAM respondents said the home was good with regard to volunteers coming into the home, with 22% saying it was poor.

- People with dementia in care homes must have the same access to health services and relationships in the community as all others, regardless of their disability. The care home sector can play a vital role supporting the development of dementia-friendly and supportive communities, and should fully engage locally and nationally with this work.

Recommendations

The report makes a number of recommendations around improving choice, care and quality of life in care homes. In addition, the Society makes an overarching recommendation from the findings of the report.

Overarching recommendation

The government and the care sector must work together to improve public understanding that people with dementia in care homes can enjoy a good quality of life. The government and the care sector should further challenge perceptions of poor practice and promote care homes as appropriate places of care for many people with dementia, rather than residences of last resort. This report has found significant evidence of the need to raise the expectations of the public and those working in the care sector about the potential for people with dementia to enjoy a good quality of life in care homes. In a context of increasing scrutiny and pressure on budgets, the future sustainability and viability of the care sector is likely to depend on these expectations being raised.
1. Meaningful choices in care should be promoted through provision of information on quality of providers, and empowerment of people with dementia, family members and health and care staff to enable choice. Our YouGov survey found that 70% of UK adults would be scared of going into a care home in the future, and 24% of DEMFAM respondents said finding information on care homes had been difficult. More needs to be done to promote information that guides, reassures and enables choices in care.

- Online information portals should be promoted, but choice will best be promoted through tools which support service users to make informed decisions about care homes when visiting them.

- The Society believes our new publication, Your handy guide to selecting a care home, is a valuable resource for supporting choice, and that care homes, local authorities, GPs and other NHS services should stock and disseminate this guide alongside our tool, This is me.

- Local authorities and regulators should do more to promote themselves as initial ports of call for people looking for information on care homes. This could include hosting information portals or ensuring data that they hold about quality is made public and accessible.

- Regulators should publish clear ratings on performance of care homes.

- Regulators must make inspection reports easy to find and understand, and should ensure, through regular inspection, that they are up to date.

- Local authorities should make use of findings from this report in fulfilling duties around promotion of choice in care homes.

- Staff across health, social care and voluntary services should be supported and empowered to effectively signpost service users to tools for choosing a care home.

2. People with dementia and their family members should have access to information and support early on in the condition, and be advised of care options for the future. This report found that the most common reasons for admission to care related to being unable to cope in the community. Insufficient access to early support and information leads to complex transitions into care.

- Rates of diagnosis of dementia should be improved, especially in England and Wales. The commitment to achieving a tangible diagnosis rate in England is to be welcomed. However, commitments in Wales remain insufficient and must be developed.

- Integration between health, social care and housing services must be prioritised to ensure people have access to support when they need it.

- When people with dementia are in need of admission to care homes, sufficient support must be provided to family members to allow them to accommodate this decision. Services such as dementia advisers should be commissioned to ensure that this happens.
6 Low expectations

3. Continued efforts should be made to improve the quality of life and quality of care for people with dementia in care homes. 68% of DEMFAM respondents said quality of care of the person with dementia was good, and 74% would recommend the care home to others. However, only 41% said the quality of life of the person with dementia was good. UK adults’ perception of how well people with dementia were treated in care homes for older people were less positive than findings from DEMFAM, with only 30% agreeing that people with dementia were generally treated well.

- The government’s cap on care costs should be kept under review. In addition, the government should ensure that funding of social care is sufficiently resourced to deliver high-quality care to people with dementia in care homes, including appropriate funding for training care home staff.

- Sector improvement systems should be promoted and strengthened with the aim of driving up quality and improving public understanding of care homes.

- Care home providers should join the Dementia Action Alliance and sign up to the Dementia Care and Support Compact. Similar local programmes should be developed in Wales and Northern Ireland.

- The Dementia Care and Support Compact should be strengthened with a specific commitment by providers to measuring quality of life of residents.

- The Dementia Action Alliance should establish a working group on improving care and quality of life in care homes.

- All staff working in care homes should have ongoing training on dementia, and providers should have to demonstrate how they are embedding learning into practice. Government, both locally and nationally, should do more to promote the importance of workforce understanding.

4. The care home sector and regulators must do more to respond to the issue of abuse in care homes. 64% of UK adults in our YouGov public poll agreed the care home sector was not doing enough to prevent abuse, and over half (53%) of UK adults said their greatest concern about a relative moving into care would be the risk that they would be abused.

- The care home sector should publicly condemn incidences of abuse when they occur.

- Safeguarding teams and regulators should work together with the care sector on agreed protocols on how to respond when incidences of abuse occur.

- Appropriate workforce regulation should be established, which includes agreed standards for practitioners, alongside appropriate working conditions.
5. People with dementia should have access to the same level of support from health and care services in care homes as they would in the community. Challenges remain in provision of health services to residents with dementia. DEMFAM found that 56% of respondents said access to a GP was good, but only 36% said access to other health services was good, and 23% said access to dentists was good, with large numbers of respondents saying they didn’t know.

- Care plans must be developed in conjunction with health services and reviewed regularly.
- NHS England, the Department of Health, Social Services and Public Safety (DHSSPS) in Northern Ireland, and Welsh Government and NHS trusts should ensure that sufficient resources are in place so that care homes do not pay for access to GP services.
- Needs assessments and strategies, such as joint strategic needs assessments, must include reference to the needs of residents living in care homes.
- People with dementia must be supported to have access to dental as well as other healthcare services.

6. Care homes should seek to be centres of dementia-friendly communities, acting as focus points for activity and engaging with the local population. Views from DEMFAM respondents on how care homes worked with volunteers and on trips out of the home revealed that 28% of respondents said homes were good in relation to volunteers coming into the home, and 26% said homes were good in relation to trips out of the home. However, respondents were more positive regarding how homes worked with friends and family of residents.

- Care homes should seek to engage volunteers, using positive engagement with relatives and friends as a foundation for development.
- Where possible, care homes should seek to ensure that residents are able to take trips out of the home, engaging with relatives, friends and residents.
- Care homes should join developing dementia-friendly and supportive communities and local dementia action alliances in order to help ensure communities can meet the needs of people with dementia and improve public faith in the work of the care sector.
What Alzheimer’s Society is doing to improve care and quality of life in care homes

Alzheimer’s Society continues to work with a range of partners to support improvements in the quality of care for, and quality of life of, people with dementia living in care homes.

The findings of this report will be used to inform our campaigning and influencing work on improving the care and quality of life of people with dementia living in care homes.

The Society also provides information to people with dementia and family members looking for a care home. The Society has produced a factsheet and Your handy guide to selecting a care home, which advise people on the key things to look for when searching for a care home. The Society’s information is accredited with the Department of Health’s Information Standard.

The Society has also produced an updated version of its tool, This is me, which can be used in care homes to provide information about the preferences and life history of the person with dementia.

Alzheimer’s Society is also a provider of specialist dementia training to care homes. The Society has a number of courses available for care home staff and managers. Where applicable, the learning outcomes of our courses are mapped on to Quality and Credit Framework dementia units.

We will be working closely with members of the Dementia Action Alliance to support sector-led improvement in care homes, as well as working locally to develop dementia-friendly and supportive communities and local dementia action alliances. We will be engaging locally and nationally with care home providers as part of this work.
Appendix B

Academic opinion on current prevalence of dementia

The Dementia UK report (2007) estimated that approximately two thirds of people living in residential or nursing home care had dementia. There were, however, several biases in the reported studies, which may have underestimated the frequency of dementia. Firstly, the number of people with dementia in residential and nursing home care has been increasing since the 1980s, and few of the studies included in the Dementia UK report had been conducted since 2000. Secondly, the recruitment strategy for most large epidemiological studies requires a positive response to an invitation to participate, which is likely to bias against people with severe dementia and those in care homes, who may be less able to participate. Studies conducted since 2000 have generally supported this viewpoint. For example, Margallo-Lana et al in 2001 reported a frequency of dementia of more than 90% in residential and nursing homes in Newcastle. More recently, Lithgow et al reported a frequency of dementia of 71% among nursing home residents in Glasgow, but with an additional 14% of residents experiencing significant cognitive impairments. In 2013, in a study examining capacity and consent for research studies, Whelan et al reported a frequency of dementia of 80% in residential and nursing homes in London and the South East. The balance of evidence therefore suggests a frequency of dementia and/or significant cognitive impairment in excess of 80% among people in the UK living in residential and nursing home care.

Studies used to inform this opinion:


Alzheimer’s Society is the UK’s leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer’s disease or any other form of dementia, visit alzheimers.org.uk or call the Alzheimer’s Society National Dementia Helpline on 0300 222 11 22 (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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