

Low expectations

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



Document purpose This report provides new evidence on the key issues affecting people with dementia living in care homes. The report summarises evidence from surveys of family members, care home staff and people with dementia about their views on care in care homes.

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

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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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Foreword



How we care for the most vulnerable in society is one of the key tests of how we as a nation are performing. Over the past 50 years, the UK has made amazing strides in the way we care for those with conditions such as cancer and HIV. We have improved treatment in hospitals and the community, and have supported those with the conditions to live full and independent lives.

Before my mum was diagnosed with Alzheimer's disease I didn't know much about the condition. Mum was a bright and fiercely independent lady – a teacher who kept active after retirement by going on archaeological digs and learning Italian. She started to show symptoms of Alzheimer's in her mid-70s and was diagnosed shortly afterwards. We wanted her to live at home as long as possible, but after her condition deteriorated and she ended up in hospital, we knew we would have to find a care home where she could be supported in the last years of her life. We were lucky. The care home my mum lived in was excellent, but we had to go through hell to find it.

Over the years I've visited a number of homes across the country, both for my mum and as part of my role as an Alzheimer's Society ambassador. I've seen examples of excellent care, and homes that I wouldn't wish on my worst enemy. It shouldn't be this way. People with dementia wherever they are should be able to count on the highest-quality care across the board.

There are 800,000 people with dementia in the UK and over 300,000 of them – more than the population of Cardiff – live in a care home for older people. Four years ago, Alzheimer's Society launched a report called **Home from home**, which detailed the experiences of people with dementia living in care homes. The report showed huge variations in the quality of care they received as well as a workforce which was crying out for more training in dementia.

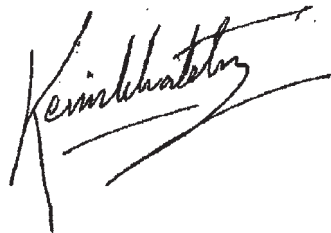
In 2013, awareness of dementia has never been higher. The government has for the first time set out a challenge to improve how they as politicians and all of us as a society are geared up to tackle dementia. Dementia has been the subject of celebrated and sensitive storylines on some of our most popular TV soaps, and leading scientists have declared the condition a global health concern on the same level as AIDS and cancer.

In this context, this report explores whether the third of those with dementia in the UK who live in a care home are experiencing the quality of life we would expect for our older years. The report covers the key factors facing someone looking for a care home, the quality of life of those living in a care home, the role of homes in the community, and the thankfully rare spectre of abuse.

What this report finds is that, while across the country there are both good and bad examples of care being delivered, expectations – from people in care homes to the staff who care for them, from their relatives to the public at large – are worryingly low. Put simply, those who don't have personal experience of care homes are scared of them and those who do don't associate good care with a decent quality of life. This is dangerous, not least because echoed through society it can become a self-fulfilling prophecy.

This report makes a number of key recommendations and looks at best practice across the country to help raise these expectations, and with them the quality of life that people with dementia receive.

Low expectations is an important part of a process which will see Alzheimer's Society working with the care sector and regulators to ensure that people with dementia, wherever they live, do not have to settle for less, but expect and indeed demand better from the care homes where they or their loved ones choose to spend their later

A handwritten signature in black ink, appearing to read 'Kevin Whately', with a large, sweeping flourish underneath.

Kevin Whately
Alzheimer's Society Ambassador

Executive summary

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.

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.
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- 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.
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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

Alzheimer's Society has made recommendations at the end of the 'Choice', 'Care' and 'Community' chapters of this report. For easy reference, these recommendations are presented below. In addition, the Society makes an overarching recommendation from the findings of the report, which is presented below and at the end of our 'Context' chapter.

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.
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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.
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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.
- The NHS Commissioning Board, 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.
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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.

1 Introduction

1.1 Introduction

There are 432,000 older people and physically disabled people in around 20,000 homes in the UK (Laing & Buisson, 2013). Alzheimer's Society's report, *Dementia UK*, estimated that two thirds of residents in care homes have a form of dementia (Alzheimer's Society, 2007). However, recent studies have indicated that at least 80% of people in care homes have dementia or significant memory problems (see Appendix B). Providing good care and quality of life to people with dementia is therefore the primary concern of the care home sector.

The need to deliver high-quality care to people with dementia living in care homes is widely recognised in public policy. Alzheimer's Society's 2008 report, **Home from home**, called for greater emphasis on the delivery of high-quality dementia care in care homes (Alzheimer's Society, 2008a). Delivering good care to this group is widely recognised in provider corporate strategies, by regulators, and also in local authority and health trust plans.

Dementia strategies and plans in England, Wales and Northern Ireland all highlight the importance of good care in care homes (Department of Health, 2009; Department of Health, 2012a; Welsh Government, 2011; Department of Health, Social Services and Public Safety, 2012). In Wales, improving care of people with dementia in care homes was also identified in the Health and Social Care Committee's report on residential care (National Assembly for Wales Health and Social Care Committee, 2012). In England, the Prime Minister's challenge on dementia established a Dementia Care and Support Compact for care providers, recognising the importance of high-quality care (Department of Health, 2012a).

There are numerous examples of good care provided to people with dementia in care homes, as well as examples of sector-wide and organisation-specific quality improvement programmes and initiatives to promote access to information and choice about care. A number of these are highlighted in this report. Furthermore, as this report demonstrates, the view of many care home staff and residents' family members is that overall quality of care in care homes is good.

However, despite many examples of good practice and care, there is evidence of ongoing challenges to the provision of high-quality care to people with dementia living in care homes, alongside examples of shocking or abusive care. Since the publication of the report **Home from home**, a number of reports by bodies and organisations such as the All-Party Parliamentary Group on Dementia (APPG), the Royal College of Nursing (RCN), and the International Longevity Centre (ILC), have highlighted ongoing challenges to the delivery of good care in care homes (APPG on Dementia, 2009; RCN, 2011; Mason, 2012; NAO, 2010; Alzheimer's Society, 2012a).

2 Introduction

These reports have drawn attention to issues such as lack of training and support for staff, need for occupation for residents and use of antipsychotic drugs in care homes. Broader challenges also remain around identification of abuse, which can occur in any care setting, and sufficient funding for care, which remains a central challenge to provision of appropriate support and care.

Furthermore, as this report demonstrates, confidence that people with dementia can enjoy a good quality of life in care homes is lacking. More needs to be done to raise expectations and aspirations for life in care homes, support people to make choices in care, promote care homes as part of the community, and improve public faith in the care home sector.

1.2 Purpose of this report

In 2008 Alzheimer's Society published the report **Home from home**, about quality of life in care homes. The report was based around carers of people with dementia living in care homes, care home staff and managers.

The findings from **Home from home** indicated that many care homes did not provide high-quality dementia care. The report identified issues such as lack of dignity and respect for residents with dementia, and lack of activities and opportunities for social interaction for residents. The report also underlined the need for close working between health and social care services and care homes, and found that many staff in care homes placed considerable importance on training and support. **Home from home** also stated a need to raise the aspirations of both the care home sector and of service users and their families about the potential and possibility for delivery of good dementia care (Alzheimer's Society, 2008a).

The intention with this report is to update our evidence from **Home from home**, and also to understand better the existing experiences and evidence around choosing a care home. This report provides an overview of key policy and evidence relating to care homes, as well as providing new evidence from family members of people with dementia, staff in care homes, and people with dementia themselves. It sets out a number of examples and case studies of good practice. These are not intended as endorsements by the Society, but as examples of how organisations and homes in the care sector are working to meet the needs of people with dementia.

1.3 Methodology

This report is informed by quantitative and qualitative research into the care of people with dementia in care homes, and people's experiences of choosing a care home. To inform this report, Alzheimer's Society developed three questionnaires relating to the quality of care of people with dementia in care homes.

All the Society's questionnaires were informed through consultation with internal staff at Alzheimer's Society or, in the case of our survey for care home staff, with members of our expert stakeholder group. Alongside our surveys, the Society also carried out desk-based research of relevant public policy relating to care in care homes. The three questionnaires are outlined opposite.

A questionnaire for family members of people with dementia in care homes

This was sent in our August edition of *Living with dementia* – the Society’s membership magazine – and was available on our website and also through some of our services and campaign groups. We received 1,139 responses to this survey, providing us with a strong evidence base of the experiences of family members of people with dementia in care homes. Throughout this report, we refer to the findings of this survey as ‘DEMfam’.

A questionnaire for care home staff

This was disseminated through a number of avenues, including a direct mailing to around 300 care homes in England, Wales and Northern Ireland, whose contact details were obtained from regulators. In addition, copies of the questionnaire were disseminated by the Society’s expert stakeholder group of colleagues from the care sector, and was available on our website and disseminated through some campaign groups. We received 647 responses to this survey. Although self-selecting, and potentially biased towards those care home staff whose managers passed surveys on to staff, this survey provides valuable evidence on the experiences of a significant number of staff working in care homes. Throughout this report, we refer to the findings of this survey as ‘DEMSTAF’.

A short survey for people with dementia living in care homes

This survey, based around Tom Kitwood’s six key psychological needs (Kitwood, 1997), was circulated through a number of staff at the Society’s services, completed in some care homes who returned copies of DEMSTAF, and was available on our website. We received 34 responses to this survey. Although this is a small sample, these surveys provide a valuable snapshot of the views of those who completed them. Based on the ways these surveys were returned, it is likely that most were completed in a small number of homes, by staff supporting people with dementia to complete them.

In addition, the Society commissioned YouGov to conduct a poll of the general public on attitudes towards dementia and care homes. This poll was of 2,060 UK adults, weighted according to demography, and was carried out between 11 and 13 December 2012. Findings from this poll are referred to as ‘YouGov public poll’. As part of the poll, the Society asked whether UK adults knew someone with dementia in a care home for older people, and 19% of UK adults responded that they did.

Statistics from our questionnaires and polls are rounded to the nearest whole number.

The care home project was guided and informed by an expert stakeholder group of colleagues from the care sector. These groups provided advice on research, assisted with dissemination of the survey, and advised on the findings of the Society’s research. The members of the group do not necessarily endorse all findings or recommendation of this report.

4 Introduction

The stakeholder group was made up of:

- Karen Culshaw, Regulatory Policy Manager, Care Quality Commission.
- Annette Darby, Group Service Manager, Adult Social Care, Dudley Metropolitan Borough Council
- Martin Green OBE, Chief Executive, English Community Care Association
- Professor Julienne Meyer, Professor of Nursing and Care for Older Adults, City University; Executive Director, My Home Life Programme
- Joanna Lenham, Practice Development Manager, Social Care Institute for Excellence
- Annie O'Mara and Keith Hoare, Worcestershire County Council
- Dr Jill Rasmussen, GP with Specialist Interest, Mental Health and Learning Disability Surrey; member of Alzheimer's Society GP Advisory Group; Royal College of General Practitioners Clinical Champion for Dementia
- Professor Louise Robinson, Professor of Primary Care and Ageing, Institute of Health and Society, Newcastle University; Royal College of General Practitioners National Clinical Champion for Ageing and Older People
- Vicky Rowley, Commissioning Manager, Older People's Mental Health Joint Commissioning Unit, Staffordshire County Council
- Jean Spencer, Team Manager, Adult Social Services, Merton County Council
- Professor Graham Stokes, Director of Dementia Care, Bupa Care Services
- Sheena Wyllie, Director of Dementia Services, Barchester Healthcare

Background and demographic information on respondents to DEMFAM and DEMSTAF can be found in Appendix A of this report.

2 Context

Summary

- 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.

2.1 Introduction

There are around 20,000 care homes in the UK, and analysis of recent studies suggests that in excess of 80% of people living in care homes have dementia or significant memory problems (see Appendix B). While there has been significant focus on delivering care to people in the community in recent years, care homes remain often the most appropriate place of care for many people with dementia, especially those with more advanced dementia.

The current focus on supporting people in the community and in other forms of housing has contributed to a shift towards higher dependency among residents in care homes. Residents in care homes are increasingly likely to have very high care and support needs, with multiple comorbidities. This is especially the case in nursing homes.

The focus of this report is on care homes which provide care to people with dementia, which are primarily care homes for older people. However, there are a significant number of care homes which provide care to people with learning disabilities, as well as smaller numbers providing care to people with other conditions, such as drug or alcohol addictions.

Those care homes which provide care to people with learning disabilities are relevant to the delivery of dementia care, since people with learning disabilities are at higher risk of developing dementia. This is especially the case in Down's syndrome, with one in three people with Down's syndrome developing dementia in their 50s, and over half of people with Down's syndrome over 60 living with dementia. Rising life expectancy among people with Down's syndrome and other learning disabilities will lead to increasing numbers of people with these conditions developing dementia.

2.2 The care home market

Historically, care homes have fallen into two groups: those that provide personal care but not nursing care (defined in England as care homes, elsewhere called residential homes) and those that provide personal care and nursing care (in England called care homes with nursing, elsewhere nursing homes). The terms nursing home and residential home remain in use in Wales and Northern Ireland, and are frequently used in England.

There are 487,000 care home places in the UK and, in total, the care home market in the UK is worth some £15.2 billion a year (Laing & Buisson, 2013). The vast majority (around 80%) of care homes are for profit, with small numbers of not-for-profit and local authority homes. The 10 largest care home providers operate around a quarter of private beds. Around two fifths are operated by small providers with one or two homes. The remainder of private beds are in providers outside the top ten largest, but with three or more homes.

2.3 Funding and accountability

The cost of care home fees is paid for through a mixture of funding from local authorities, the NHS and individuals and their families. Where care provided through the NHS is free at the point of need, an enforced division between health and social care means that local authorities' contributions to the costs of care are means tested, based on individual's ability to pay. This means that many people with dementia and their families have to pay for the costs of care, whereas people with other conditions have their care provided free at point of need through the NHS. A small proportion of places in care homes are funded through NHS Continuing Care, but eligibility criteria for this funding are very tight.

Those people not meeting financial criteria set by local authorities have to pay the costs of their care from their own assets, income, pension and benefits. In addition, because of limited resources, local authorities can only afford to pay a certain amount in care home fees. Those wishing to pay for places in homes that cost more than the local authority will contribute, can top up from their own or their family's assets.

The current system of funding of social care means that many people with dementia and their families face significant care costs, sometimes running into hundreds of thousands of pounds. This places considerable pressure on family finances. Proposals to limit these excessive costs have been proposed by the Commission on Funding Care and Support (Commission on Funding Care and Support, 2011). The UK government has announced that it intends to implement proposals based around the Commission's. The government has stated that the means-tested threshold at which the state pays a proportion of care costs will rise to £123,250 in 2017, from £23,250 now. In addition, care costs will be capped at £75,000, although this is higher than proposed by the Commission.

According to a Laing & Buisson report, 43.4% of older care home residents are self-funders, with 43% having their fees paid in full by local authorities or through NHS Continuing Care. The remaining 14% are local-authority-funded residents who top up their care. Accounting for those who pay a proportion of their fees (top up local authority fees) alongside those who solely self fund, 57% of older residents pay a proportion of their care costs (Laing & Buisson, 2013). Alzheimer's Society's Dementia tax reports in 2008 and 2011 demonstrated that those who pay towards the costs of care come from all social classes and are not restricted to the affluent (Alzheimer's Society, 2008b; 2011a). Many people with dementia and their families end up paying huge amounts for the care that they receive.

Although self-funders represent a significant number of occupants in care homes, local authorities (or health and social care trusts in Northern Ireland), play a crucial role in the care home market. Alongside funding the care of many residents, authorities and trusts also have responsibilities relating to safeguarding of all residents in care homes. In England, local authorities also have responsibility for promoting workforce development, as well as having a role in shaping the care market and provision of information to service users, including those funding themselves. Wales and Northern Ireland also place duties on local authorities relating to information provision, workforce development and improvement.

2.3.1 Financial stability

There are considerable challenges to the funding of care services in the UK. Firstly, there is the significant black hole in the funding of social care, with insufficient funds to meet demand and need. Local authority funds for care services are correspondingly under intense pressure. This has led to a raising of eligibility thresholds for accessing support, which adversely affects people living in the community, but is likely having a knock-on effect of earlier and crisis-driven admissions to care homes, owing to lack of community support.

In addition, pressure on local authority finances means that many authorities are very restricted in terms of what they can pay for care in care homes, contributing to increased topping up or restricted choice. Increasing demand and continued restriction on local authority budgets is likely to exacerbate this situation and raises questions as to how improvement in standards can be fostered and whether good care can be delivered for the price local authorities can pay.

Concerns also remain relating to the financial stability of the care home market, which was underlined by the collapse of Southern Cross, then the UK's largest care home provider. Although the collapse of Southern Cross did not have a significant impact in terms of homes closing, and the provider had specific challenges in terms of its business model, its collapse raised questions around the future viability of the care market and caused significant concern among many residents and staff. The issue of financial stability of care homes is currently the subject of a Department of Health consultation (Department of Health, 2012b), and concerns remain over other business models in the sector.

2.3.2 Regulation

Care homes are regulated services and must be registered with statutory regulators and comply with standards. Different regulators exist in England, Wales and Northern Ireland. In England, care homes are regulated by the Care Quality Commission (CQC), in Wales by the Care and Social Services Inspectorate Wales (CSSIW), and in Northern Ireland by the Regulation and Quality Improvement Authority (RQIA).

The emphasis and detail of these regulations varies considerably. The CQC's essential standards focus on 28 outcomes drawn from the CQC 2009 regulations (CQC, 2010). In Wales, compliance is assessed against the 2004 national minimum standards, which are drawn from the 2000 Care Standards Act and the 2002 Care Homes (Wales) regulations (CSSIW, 2004). In Northern Ireland the RQIA standards are extensive and significantly more prescriptive in terms of the specific parameters against which care homes should be performing (DHSSPS, 2008; 2011).

All three regulators are compliance regulators, meaning providers are deemed compliant with the regulations if they meet standards. Regulators have the powers to issue warnings, fine, prosecute and even close care home providers failing to meet standards. In England, the CQC and its predecessor, the Commission for Social Care Inspection (CSCI) used to operate a star rating system, whereby providers would be given a rating based on graded performance. This system was dropped in 2010.

The following criticisms have been levelled at the systems of regulating care homes:

- There remain ongoing concerns that regulators remain insufficiently funded to drive up the quality of care in care homes.
 - The CQC in England has been criticised for failing to make regular inspections of care homes. The CQC has now introduced annual inspection of care homes from 2012 onwards, which is welcome. Evidence from CQC 2011/12 State of care, prior to this requirement, indicates that not all homes were being inspected annually (CQC, 2012a). It is hoped that the new requirement from 2012 onwards will ensure homes are inspected annually. In Wales, CSSIW's latest report indicates 100% inspection rates.
 - The CSSIW does not publish assessments of the extent of its enforcement activities across the sector, or all Wales-level data on compliance.
 - In England, the CQC has been criticised for not acting on whistleblowing in response to incidences of abuse or unacceptable care (House of Commons Committee on Public Accounts, 2012).
 - Issues with the consistency of inspections and understanding and knowledge from inspectors have also been widely reported.
 - In addition, both the sector and patient organisations have called into question the compliance model of regulation. Regulators have been called on to regulate for quality, to improve the services people receive, or to look at regulating the care market, including commissioning of care, rather than simply focusing on compliance.
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2.4 Dementia and care homes public policy

Existing public policy sets out a range of areas for progress on improving care of people with dementia in care homes. In England, one of the objectives of the National Dementia Strategy for England (NDSE) is living well with dementia in care homes. The NDSE highlights evidence from the Society's report, **Home from home**, that carers felt relatives did not have enough to do, and staff felt they needed more time to provide opportunities for interaction and activities. The strategy calls for identification of dementia champions, commissioning of in-reach teams and appropriate support services, and emphasis on reducing the use of antipsychotic drugs (Department of Health, 2009). The strategy was supported by £150 million of funding in its first two years, with additional resources given for specific areas in subsequent years.

The Northern Ireland dementia strategy, published in November 2011, also identified the need to improve care in care homes. The strategy recognises the need for dementia-friendly care, and states that the health and social care board will establish standards in commissioning to encompass staff knowledge, environmental audit, life history work and building links with the community (DHSSPS, 2011). While initially not supported by new investment, subsequent to the publication of the strategy, the Northern Ireland Assembly has committed to £1 million of funding to support its implementation, although it is unclear the proportion of this allocated to improving care in care homes.

In Wales, the national dementia vision for Wales highlights the importance that health and social staff are given sufficient training to deliver high-quality care to people with dementia (Welsh Government, 2011), but the vision does not address care homes specifically. Likewise, the need to improve care in care homes is not specifically identified in the Welsh government intelligent targets (Welsh Government, 2011 [online]). However, stakeholder dementia action plans produced by the Welsh Government do identify improving care in care homes, and the need for action on improving care in care homes is recognised by the Welsh Assembly and Welsh Government (Welsh Government, 2010 [online]).

In March 2012, David Cameron launched the Prime Minister's challenge on dementia. The challenge focuses on improving investment in research, building dementia-friendly communities, and improving health and social care services (Department of Health, 2012a). The first progress report of the champion groups of the Prime Minister's challenge identified significant action being taken across health and care, research, and building dementia-friendly communities (PM challenge champion groups, 2012).

The Prime Minister's challenge recognises that, while many care homes offer excellent support to people with dementia, some are not doing enough, and that staff must have the knowledge and skills to enable residents to lead as fulfilling a life as possible. The challenge established a Dementia Care and Support Compact, which makes commitments for signatory providers around quality and inclusion. At time of the status report for the Prime Minister's challenge in November 2012, the compact was signed by 42 signatories representing services which deliver care to over 200,000 people (PM challenge champion groups, 2012).

2.5 Sector quality improvement

Care providers are responsible for the care in their homes, but a number of other bodies have interests, responsibilities and a stake in improving care in care homes.

Larger providers will often have strategies and programmes for improving quality of care, including specific strategies relating to dementia. In addition, representative bodies such as the English Community Care Association (ECCA) and the Registered Nursing Home Association have conferences, workshops and other systems of quality improvement. In addition, providers which are members of these groups have to agree to terms of membership.

There are a wide range of other bodies playing a role in quality improvement. Charities and other bodies such as the Social Care Institute for Excellence promote good practice in care homes. A number of academic institutions are also playing a role in promoting quality, either through programmes or training tools, including the Bradford Dementia Group, the Stirling Dementia Centre and the University of Worcester.

My Home Life, whose partners include City University, ECCA, Age UK and Dementia UK, focuses on eight themes around personalising care, supporting people through the care journey and supporting leadership. The NHS Institute for Innovation and Improvement has also run a dementia programme focusing on improving communication in care homes and on how care homes work with external organisations.

Alongside the Dementia Care and Support Compact, a new dementia pledge has been launched. The pledge sets out four principles which care providers should nurture across their workplace:

- know the person who is living with dementia
- quality of life, not quality of care
- everybody has a leadership role
- value-focused care. (ECCA, 2013)

Additionally, there are a number of rating agencies for quality of care homes, focused on supporting choice, and a number of local authorities have also developed local quality marks and improvement programmes.

2.6 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.

3 Choice

Summary

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

3.1 Introduction

The decision to move into care is a complex one, involving the person with dementia, their family, and health and social care professionals alongside care home staff. For people with dementia, decisions to move into care are normally made by family members alone, or family members in consultation with the individual. This is often because people with dementia going into care are at moderate or late stages of dementia, and may struggle or be unable to make decisions themselves.

The process of transition into a care home can be distressing for individuals and their families, and is often made at a point of crisis. Access to information and support to help families and individuals make this choice are crucial, and current evidence on these areas will be explored in this chapter.

3.2 Reasons for going into care

Decisions for a person with dementia to go into care can frequently be made at times of crisis, for example when someone can no longer be supported at home or after an admission to hospital, rather than as a planned and considered choice. An Alzheimer's Society report, *Counting the cost*, found that a third of people admitted to hospital from their own home were discharged into a care home (Alzheimer's Society, 2009). At such times, pressure to find a home can be acute, and the ability of families and individuals to make informed choices is impaired. The prospect of going into care is also one which is seen as frightening and uncertain, and can be fiercely resisted. This makes access to meaningful information, and awareness of where this information can be found, crucial.

Our YouGov public poll uncovered significant public fear about going into a care home; 70% of UK adults responded that they would be scared of going into a care home in the future (31% very scared, 40% fairly scared).

DEMFAM asked respondents the reason for the person with dementia being admitted to care. Responses were coded under key themes, and those themes highlighted by more than 10% of DEMFAM respondents are highlighted below:

- 33% (379): 'I was unable to look after them / cope with increasing demand.'
- 26% (294): 'They were no longer able to live independently / needed 24-hour care.'
- 23% (263): 'Safety issues / becoming a danger to themselves'
- 16% (186): 'Admitted / advised by hospital / social services / community nurse'
- 14% (164): 'Had challenging behaviour (abusive/aggressive etc)'
- 14% (156): 'Carer had health issues of their own / failing health'
- 11% (125): 'Personal care/hygiene issues (incontinent / double incontinent etc)'

Some respondents' answers could be coded into several key themes, so these do not add up to 100%.)

These findings suggest that challenges with coping in the community, or difficulties responding to progression of dementia, are the major factors leading to admission to care among DEMFAM respondents. Concerns about carer health and ability to cope also feature very strongly in responses.

Other research and policy evidence on transitions to care homes support the DEMFAM findings that being no longer able to cope is a significant factor affecting people with dementia being admitted into care. Diagnosis rates of dementia remain low in England and Wales, and diagnosis often takes place late in progression of the person's condition, meaning they may struggle to get help when it may be of benefit. This could be contributing to difficulty coping in the community (Alzheimer's Society, 2013).

In a paper on managing transitions, which formed part of the My home life literature review, authors identified that many carers cared for people with dementia at home until needs reached breaking point (O'May, 2007). Alzheimer's Society's report, **Support. Stay. Save.** identified that lack of support in the community may be contributing to early admission to care homes as a result of people being unable to cope (Alzheimer's Society, 2011a). Furthermore, the National Audit Office (NAO) 2007 report on dementia outlined that much spending on dementia was late in people's condition (NAO, 2007).

There will always be an element of crisis admission to care homes, as a result of falls and rapid changing of need. However, the above evidence suggests that many people with dementia and their carers are not getting enough support in the community, or are being admitted to care later than would be in their best interests. When admissions to care homes are made at crisis points, they can be challenging for care homes to manage and for residents to adapt to.

Those making decisions may already be under considerable stress or have limited time to make what are complex and difficult decisions about the future. As our YouGov public poll has identified, the prospect of going into care is frightening, underlining the importance of information and support.

Managing people's care after diagnosis and better provision of services in the community could potentially enable people with dementia to remain at home for longer, and could also help ensure that transitions to care are easier to manage. Furthermore, early provision of information and advice on moving into care homes should be made as accessible and available as possible.

When someone might need admission to care, family members must be given support to understand and accommodate this need, to avoid people reaching crisis.

3.3 Finding information on care homes

Information is known to be essential to the promotion of choice and service user control, and is widely seen as a valuable means of driving up quality. There are a range of sources of information about what defines high-quality care in care homes, as well as information on the adherence of individual providers to standards.

Local authorities and trusts in Northern Ireland have duties and responsibilities around provision of information on care options, and play a key role in assessing need for the majority of social services users. As such, they play an integral role as an initial or early port of call for information.

Information is also produced by regulators in Wales, England and Northern Ireland who provide information on adherence of care homes against standards, and publish inspection reports. In addition, a wide number of organisations produce information on choosing a care home, including specific information on choosing a home for people with dementia. Charities, including Alzheimer's Society, provide factsheets on choosing a care home, as do care providers such as Bupa and Barchester. Alzheimer's Society have also produced **Your handy guide to selecting a care home.**

A number of web-based platforms and portals relating to information on choosing care homes have been established. These portals outline evidence on the quality of individual providers, based on evidence from regulators, alongside information from providers themselves. Examples include Social Care Institute for Excellence's (SCIE) Find me good care, and the Department of Health's provider quality profiles, which will be based on a new universal health and care information portal.

With the DEMFAM survey, the Society was interested in understanding the experiences respondents had when choosing a care home:

- Our DEMFAM survey found that 50% of respondents (572) reported finding information on care homes was easy:
 - 10% (113) very easy
 - 40% (459) quite easy.
- However, nearly a quarter (24% – 278 respondents) said it was difficult:
 - 7% (76) very difficult
 - 18% (202) quite difficult.

The Society also sought to gain a better understanding of how respondents found information on care homes. DEMFAM respondents strongly emphasised the importance of personal visits in choosing a care home:

- Responding to an open question 'How did you choose a care home?', 45% of respondents (514) responded with an answer relating to 'personal visits / vetted with the aid of family/ talked to staff when visited'. This was more than twice the proportion as the next most common answers given, which were relating to 'location / close to family', which was highlighted by 22% of respondents (249).

Furthermore, when asked to select from a range of options for where respondents found information on care homes, the following options were the most frequently selected:

- 59% of DEMFAM respondents (670) said they got information from care homes directly.
- The next most common items selected were social workers (40% – 455) and other health and care professionals (26% – 295).
- Just under a quarter (23% – 261) of respondents had obtained information from the local regulator (either the CQC, CSSIW or RQIA).
- Over a fifth (21% – 237) of respondents said they got information from the local council.
- The same number (21% – 237) said they got information from Alzheimer's Society services.

DEMFAM findings indicate that many respondents were able to find information on care homes relatively easily, but a quarter found it difficult. This indicates significant room for improvement in access to and dissemination of information on care home options. The Society remains concerned that a gap in the provision of information about care homes and the quality of care provided still exists.

It is welcome that DEMFAM shows respondents are approaching care homes directly. Seeking information directly from care homes is the most effective means of assessing the quality of dementia care delivered. While web-based portals for promoting choice are welcome, we do not see these as being effective mechanisms for making decisions, beyond getting first impressions about provision and types of services available. Enabling choice should focus on supporting people to visit and appropriately assess care homes and tools, and information should focus on this.

It is also welcome that respondents were speaking to health, social care and voluntary sector professionals as part of the process of gathering information on care homes. The Society believes that this indicates that many respondents were supported in the process of finding information on care home options and choosing a home. It is important that health, social care and voluntary sector staff are informed and supported to signpost and empower decision-making appropriately, and are knowledgeable about appropriate tools and information sources.

The small number of DEMFAM respondents saying they got information from regulators underlines the importance of the CQC and other regulators being more active in the promotion of the evidence they have. We welcome recognition of this need in the CQC's draft strategy for 2013–16. The Society believes that all individuals making a decision about care should be signposted towards information held by regulators, or be presented with this information in some format.

Regulators represent a key avenue of data and evidence on the performance of care homes, and as such should work with other organisations and with front-line health, social care and voluntary sector professionals to share this data. To this end, the Society welcomes moves by the CQC on syndication of data with other organisations, such as SCIE's Find me good care and the DH's provider quality profiles, as well as with local authorities. These developments must be mirrored by regulators in Wales and Northern Ireland.

In England, the CQC abandoned a star rating system in 2010 which, while widely recognised as flawed, did still provide some information about quality of providers. Subsequent plans for a system of independent excellence awards in adult social care were aborted due to lack of support from the sector, and a number of private rating systems have developed since. At the time of writing, the Nuffield Trust has been commissioned to explore the potential for a ratings system in health and social care. The Society has fed into this consultation and looks forward to its conclusions.

Inspection reports in England, Wales and Northern Ireland still do not provide sufficient detail to inform choice and, owing to problems with regular inspection, can be out of date. Regulators, government and the care industry itself should consider how to provide valuable and meaningful information on quality of providers to service users and their family members. Inspection reports must be easy to find and understand, and every care home must be inspected at least annually to ensure that information is up to date. Inspection reports should provide a recognised comparable rating about the quality of a provider. Local authorities should also ensure they provide information on choices in care, and direct service users to evidence on performance and tools to support choice.

The Society's publication **Your handy guide to selecting a care home**, published in January 2013, is intended to support and aid individuals in assessing quality in care homes during visits. Given that most respondents highlighted visiting homes as the key means by which they got information on care homes, we believe this guide can play a key role in supporting people to determine quality of care in the homes they visit.

3.4 What is important when choosing a care home

There are a range of factors which influence quality of care and quality of life for people with dementia living in care homes, including staff understanding of dementia and opportunities for activities. These, alongside a range of other areas, such as design of the home, are identified in current tools on choosing a care home.

Through DEMFAM, Alzheimer's Society sought evidence from respondents about what aspects were considered most important when choosing a care home. When asked to select three options from a list of 10 choices, respondents replied as follows:

- 87% (992): staff understanding of dementia
 - 51% (576): friendliness of staff
 - 44% (498): how clean the home is
 - 42% (484): how close the care home is to the family of the person with dementia
 - 32% (359): activities residents were offered
 - 25% (282): quality of food in the home
 - 19% (221): costs of care
 - 15% (173): how the home was designed
 - 12% (133): how close the home was to where the person with dementia used to live
 - 11% (125): access to outdoor space
 - 3% (30): did not respond.
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The Society also asked UK adults in our YouGov poll what would be the most important thing for them if they were looking for a care home for a close relative:

- 48% of UK adults said training of staff was the most important factor
- 13% of UK adults said proximity to other relatives
- 11% of UK adults said cleanliness
- 9% of UK adults said price
- 6% of UK adults said availability of activities
- 3% of UK adults said other
- 10% of UK adults said don't know.

Although both sets of responses were prompted, UK adults in our YouGov poll and DEMFAM respondents both identified similar areas as being important.

The evidence points very clearly to recognition of the vital role that staff can play in the care of people with dementia. Respondents identified staff understanding of dementia as being one of the most crucial areas of importance. Training and learning must continue to focus on improving and developing staff understanding of dementia to meet this need; this is discussed further in Chapter 4.

Other areas were less commonly identified, despite being important to provision of high-quality care to people with dementia. Design and access to outdoor space can be important in terms of quality of life, yet these areas scored relatively low. This may be a reflection that other issues around staffing, cleanliness or ease of visiting by family are deemed more important, or that respondents are unclear of the role that design and access to outdoor space can have, or have low expectations that the person with dementia can engage with elements of design or outdoor space. The Society believes there is a case for the promotion of information and evidence on the benefits of good design or access to outdoor space to carers.

Similarly, while activities were identified by 32% of respondents, this is perhaps low considering the crucial role that activities and occupation can play in the delivery of good care. Furthermore, only 6% of UK adults responding to our YouGov poll identified that the availability of activities would be the most important factor for choosing a care home. The Society believes that the care sector and patient organisations should do more to highlight the importance of activities and occupation in the provision of high-quality care to people with dementia in care homes.

3.5 Moving between homes

A move into care is not a one-off event, and people with dementia may need to move again after first entering care. Reasons vary for people moving from one type of care home to another. In some instances, people's needs develop to a point where the home they are in may no longer be able to cope with them. For example, people may initially be admitted to a care home without nursing, but later require nursing care and therefore have to move. This move may be due to progression of dementia or because of another factor, such as a fall or another disease. Other reasons for moving between homes include someone moving to live near family or friends, the closure of a home, or because concerns are raised about the quality of care being received.

Almost a third (32% – 363) of DEMFAM respondents reported that the person with dementia had to move homes after first going into care. Those respondents who said the person had moved were then asked why the move took place:

- 45% (164) said this was because their care needs became too high for the home to cope
- 22% (80) said it was because the quality of care was poor
- 7% (26) said it was because the home closed
- only 1% (3) said the reason was the fees being too high
- a further 39% (141) responded 'other'
- 1% (4) did not answer this question.

The fact that nearly a third of respondents said the person with dementia had to move care home is an arresting statistic. While there is a lack of clear evidence on the impact of moving between homes, it is known that moving can be a difficult and disrupting process. Transitions into care can be complex and it takes time for staff in a home to understand the needs of new residents and to provide personalised care. The Society believes further investigation of moves between homes, by regulators and the sector, would be welcome.

Instances of a move to a new care home leading to better care or quality of life are to be welcomed. However, the Society remains concerned that a significant number of people with dementia are not getting good care in the first instance, and are therefore having to move.

Such frequency of transitions within care – as indicated by DEMFAM – strongly suggests that decisions to move into care should be seen as a step within a continuum of care, rather than a single large event. Provision of more forms of supportive housing and support in people's own homes may be elements in preventing premature admission, as will training care home staff so they are able to cope with progressively complex dependency needs. However, the Society also believes that care homes should not be seen simply as final step in people's care, but as an appropriate place of care for many people with dementia.

3.6 Recommendations

Recommendation 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 that data 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.

Recommendation 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.
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Case study 1

Alzheimer's Society's Your handy guide to selecting a care home

Project description

Alzheimer's Society has produced a handy guide to choosing a care home. This guide is based on our factsheet *Selecting a care home*, and is developed from a previous publication we produced in 2008 following publication of our report, **Home from home** (Alzheimer's Society. 2008).

The guide sets out a range of key elements of good care in care homes, and is intended to be used by people with dementia and family members visiting homes to score their performance, which aids comparison. The guide covers a range of areas such as the design and layout of the home, staff, and working with health and care professionals.



Why it was needed

The Society had previously produced a guide to choosing a care home, and has a robust factsheet on the topic. The new guide has been updated, adheres to the Department of Health's Information Standard, and now includes new sections.

The evidence from this report has demonstrated that many family members gather information on care homes directly from homes themselves. This underlines the importance of providing tools to enable family members to assess the quality of homes when visiting them.

Outcomes and evaluation

The Society has only recently published this guide, and therefore has not yet evaluated its impact. However, we are confident it will be a valuable addition to our existing information.

4 Care

Summary

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 responding to our YouGov poll 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 poll 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.

4.1 Introduction

People with dementia in care homes need high-quality care, provided by trained staff in environments which promote and support a good quality of life. There are a number of elements which are likely to contribute to good care and which support good quality of life.

This section outlines the key evidence from our surveys about the care and support of people with dementia living in care homes, and identifies the key issues affecting the delivery of good care and promotion of quality of life.

4.2 Quality of care and life

These two are interconnected: for a person with dementia living in a care home, quality of care can be seen as one element of quality of life. A resident may receive good care from care home staff, but still face barriers to enjoying a good quality of life. The opinions and views of different groups around what constitutes quality of life and quality of care are likely to vary, and are subjective. Family members, staff and residents themselves may all have differing views on this, so there will be varying views on whether this is being delivered.

The importance of delivering high-quality care and ensuring good quality of life are strongly emphasised in regulations in Wales, England and Northern Ireland. Assessing quality of care is complex, and requires a range of techniques and tools for assessment. Programmes such as dementia care mapping can be effective means of assessing the quality of care in an environment. Tools, such as the short observational framework for inspection (SOFI), can be used to capture the experiences of service users who are unable or struggle to express themselves. Alzheimer's Society has also outlined a number of standards we believe are important to quality of care in care homes, and standards exist in training programmes and sector improvement initiatives.

While tools exist for assessing quality of care, there remains a lack of evidence about the quality of care within care homes. Reports on compliance from the CQC suggest that large numbers of care homes in England do not meet regulatory standards, but these are not necessarily indicators of quality. A 2008 report by CSCI found that many care homes, despite being rated good or excellent, were still not delivering high-quality dementia care (CSCI, 2008). Furthermore, it is possible that a care home providing overall good care fails to meet standards, for example due to minor administrative errors.

Through the surveys informing this report, the Society has sought to assess perceptions of respondents around quality of life and quality of care of people with dementia in care homes. Findings from DEMFAM provide a contrast between perceptions of quality of care and quality of life. Overall satisfaction with the quality of care in care homes was high.

- Only 8% of DEMFAM respondents (87) said they thought the overall quality of care was poor, with 19% (220) saying satisfactory and over two thirds (68% – 774) saying good or very good.
- Furthermore, when asked whether respondents would recommend the care home to others, nearly three quarters (74% – 841) said that they would, and only 11% (129) would not; 15% (169) didn't know.

UK adults responding to the Society's YouGov poll were split quite evenly in their responses relating to how well people with dementia are treated in care homes for older people:

- 30% of UK adults agreed people with dementia were generally treated well (3% strongly agreed and 27% tended to agree)
 - 32% of UK adults neither agreed nor disagreed
 - 24% of UK adults disagreed (5% strongly disagreed and 19% tended to disagree)
 - 15% of UK adults said they didn't know.
-

When asked to rate the quality of life of the person with dementia in the care home, DEMFAM respondents were significantly less positive than they were about quality of care of the person with dementia.

- Only two in five (41% – 462) said quality of life of the person with dementia was good, with 28% saying it was poor (314 respondents) and 30% (339) satisfactory.

Similarly, findings from DEMSTAF and our YouGov survey indicate that many staff and UK adults do not believe people with dementia in a care home can fully enjoy a good quality of life:

- Only 26% of DEMSTAF respondents (167) said people with dementia enjoy a good quality of life, with 9% (58) responding no and 61% (396) saying to some extent; 4% (26) said they didn't know, or didn't answer.
- Our YouGov public poll found that nearly 3 in 5 (59%) of UK adults agreed that people with dementia can have a good quality of life in a care home, with 12% of UK adults saying they strongly agreed and 47% of UK adults saying they tended to agree.

However, findings among people with dementia who completed our short survey were more positive about quality of life:

- Among people with dementia who completed our short survey, around three quarters (25 of 34 respondents), said they were happy living in the home. Six (18%) said they were happy sometimes, and two (6%) said they were not happy. One respondent did not respond.
- When asked whether they could be themselves in the home, 88% (30) of people with dementia said yes, with 9% (three) saying sometimes. One respondent did not respond.

DEMFAM figures on quality of care are a significant statement of the high regard for the care that people with dementia receive in care homes, as are the findings of our survey of 34 people with dementia. While questions differ in exact wording, DEMFAM findings are broadly in line with the findings of the report **Home from home**, which also identified high levels of satisfaction with quality of care. The You Care rating survey also found positive responses from residents in care homes (Ipsos-Mori, 2013). However, the less positive responses from DEMFAM relating to quality of life highlight an apparent contrast between the delivery of good care and perceptions of good quality of life of people with dementia in care homes. Furthermore, there remains a small but persistent number of accounts of poor and unacceptable quality care.

The view of the general public was less positive regarding how well people with dementia are treated in care homes. This may be in part because of high-profile cases of abuse, but it also indicates a lack of public confidence in the care home sector at present. However, it shows a divide between the views of the general public and that of staff and family members, which must be overcome.

The Society's report, **Home from home**, concluded that many carers, family members and staff had low aspirations relating to the quality of life which people with dementia can enjoy in care homes. The findings from DEMFAM and DEMSTAF suggest that these aspirations and remain low. Other reports, such as that of the National Assembly for Wales Health and Social Care Committee, support this conclusion (National Assembly for Wales Health and Social Care Committee, 2012).

In addition, while findings from people with dementia responding to our survey, and DEMFAM and DEMSTAF, around quality of care are positive, evidence suggests that ongoing issues persist. The National Assembly for Wales Health and Social Care Committee's report on residential care found continuing challenges for quality of care. The CQC's State of health and social care in England report for 2011/12 found that 80% of nursing homes and 84% of residential homes were meeting standards on monitoring quality of care. Only 77% of nursing homes and 84% of residential homes met standards on staff numbers (CQC, 2012a).

The Society believes that the care sector must do more to promote good practice, and should work to raise the aspirations of family members of people with dementia, staff and the general public. The Dementia Care and Support Compact (part of the Prime Minister's challenge on dementia) and the National Dementia Declaration are sound building blocks for such sector quality improvement. However, more care home providers must sign up to the compact and also join the Dementia Action Alliance. Moreover, significant benefit – in terms of both reputation and quality – could be achieved by strengthening the Dementia Care and Support Compact. Providers should also sign up to the Dementia Pledge.

More also needs to be done from a public policy perspective to provide evidence about the quality of life of people with dementia in care homes. Inspection of homes by regulators should seek to develop evidence around views on quality of life in care homes, and whether it is being maintained.

Training, learning and culture in care homes should all promote the belief that people with dementia can enjoy a good quality of life, while recognising that quality of life may be perceived differently earlier in one's life. Tools, such as the Society's survey for people with dementia, could be used by providers and inspectors to elicit views from people with dementia about their quality of life and experiences of living in a care home.

However, it must be recognised that resources are needed to ensure effective quality improvement in the care home sector. The Society echoes concerns expressed elsewhere that cuts to local authority funding, and corresponding implications for care home fees, are significant limiting factors on quality improvement. The government's intentions around capping care costs and raising the means-tested threshold are welcome. However, the cap is set at a level that means many people will continue to pay large care costs. In addition, these proposals will not release new money for social care, which is urgently needed. Decisions around cuts to local government finances should also be revisited, as these are likely to be detrimental to efforts to improve quality of care and quality of life in care homes.

4.3 Specific areas of life in care homes

As outlined, both **Home from home** and this report found that respondents rated overall quality of care that people with dementia received as generally positive. However, **Home from home** uncovered a number of issues relating to specific aspects of quality of care and quality of life for residents. The Society is interested in looking at these areas in more detail to develop an understanding of any shift in experiences.

Aspects leading to good quality of life for people with dementia in care homes are likely to vary with the severity of dementia and also relating to the individual (Cahill and Diaz Ponce, 2011). However, issues such as interpersonal relationships, the environment, and the opportunity to be involved in activities and occupation, are widely associated with a good quality of life (Alzheimer's Society, 2008a; Reed, 2007).

Reed, in the literature review for the My home life project, outlined that there were numerous factors relating to quality of life, but drew these together under three broad themes of:

- environment
- activities
- relationships (Reed, 2007).

The Society broadly agrees with these three categories, and we have outlined our evidence based around these three themes. This is not intended as an exhaustive assessment of the themes, but as a review of our findings under these themes.

4.3.1 Environment

There is significant evidence that the environment that people with dementia live in can have profound implications for their quality of life. Dementia can make it difficult for people to negotiate environments, potentially increasing the risk of accidents. Furthermore, many people with dementia are prone to walking about, and need environments which can enable this while remaining safe and secure.

Access to kitchens, reminiscence rooms, destination points and other elements of design can support the delivery of good care for residents with dementia (Mason, 2011). These places can also be important as focuses for activities and occupation, as well as supporting nutrition and hydration of residents. Outdoor space can be stimulating for people with dementia and also a focal point for activities. Promoting access to outdoor space is widely recognised as important in design guidance on care homes. All care homes have to comply with environmental criteria set out in regulations. These vary across England, Wales and Northern Ireland.

The Society asked a number of questions about environments in our surveys.

Respondents to both DEMFAM and DEMSTAF were broadly positive about the design of care homes, cleanliness of the home and access and quality of toilets (see Tables 1.1–1.4).

Table 1.1 How the home was designed and planned

Survey	Positive		Negative		Satisfactory	Don't know/ didn't answer
DEMFAM	58% (658)		11% (122)		28% (316)	4% (43)
	30% (340) good	28% (318) very good	7% (81) poor	4% (41) very poor		
DEMSTAF	61% (493)		14% (89)		24% (154)	2% (11)
	33% (216) good	27% (177) very good	11% (69) poor	3% (20) very poor		

Table 1.2 Bathrooms and toilets

Survey	Positive		Negative		Satisfactory	Don't know/ didn't answer
DEMFAM	70% (796)		7% (83)		19% (220)	4% (40)
	32% (364) good	38% (432) very good	5% (65) poor	2% (18) very poor		
DEMSTAF	68% (442)		7% (48)		23% (152)	1% (5)
	35% (226) good	33% (216) very good	5% (35) poor	2% (13) very poor		

Table 1.3 Cleanliness

Survey	Positive	Negative	Satisfactory	Don't know/ didn't answer
	76% (860)	5% (55)		
DEMAM	33% (374) good	43% (486) very good	3% (39) poor	1% (16) very poor
			18% (201)	2% (23)

Table 1.4 Access to gardens or outdoor space

Survey	Positive	Negative	Satisfactory	Don't know/ didn't answer
	62% (703)	14% (162)		
DEMAM	29% (326) good	33% (377) very good	9% (98) poor	6% (64) very poor
			21% (239)	3% (35)
	72% (463)	12% (76)		
DEMSTAF	28% (183) good	43% (280) very good	6% (40) poor	6% (36) very poor
			15% (98)	2% (10)

Our survey of people with dementia asked two questions relating to the environment respondents were in.

- 82% of people with dementia (28 respondents) said they felt they were comfortable in the home; 12% (four) said sometimes and 6% (two) said they were not comfortable.
- 62% people with dementia (21 of 34 respondents) said that the care home felt like their home, with around a quarter (eight respondents) saying sometimes and 12% (four respondents) said the home did not feel like their home. One respondent did not answer.

The Society believes these DEMFAM and DEMSTAF results indicate positive attitudes from respondents towards the practical elements of care homes. Adapting existing care home environments can be complex and costly, so it is welcome to see positive views on these existing environments of care.

However, challenges with care home environments have been recognised in the literature and by professionals in the sector. **Home from home** identified that some respondents outlined challenges in terms of access to outdoor space. Similarly, the research literature for My home life outlined this as a challenge to many homes. Recognising the need to improve environments of care, the Department of Health in England has allocated £50 million to NHS trusts and local authorities to tailor acute care wards and care homes to people with dementia.

Environmental features, such as high fences or doors that can't be opened, can contribute to a feeling of confinement. While our sample of respondents with dementia was small, and most felt comfortable, it is notable that the responses to our question about whether the care home felt like the person's home elicited the lowest number of positive responses of any question in the survey, with only 62% (21 respondents) saying the care home felt like their home. Steps should be taken to make care environments feel domestic.

Where environments remain poorly designed to meet the needs of people with dementia, efforts should be made to improve them. This should include promoting access to gardens and outdoor space. The focus on new-build care homes should be on how environments can support good quality of life for residents, and existing good practice design guidance should be considered early on in building processes.

4.3.2 Relationships

Relationships within care homes are essential to ensuring people with dementia get the support they need. Findings from Chapter 3 underline the fact that staff, their understanding of dementia, and their friendliness, are key factors when selecting a care home.

The Society has focused on views of staff understanding and on engagement and involvement of people with dementia in care in this section. However, a much broader spectrum of relationships within care homes is important, such as those between residents, with family members of residents, and with other professionals. The Society has covered elements of relationships with health and care professionals, volunteers and others in Chapter 5.

4.3.2.1 Involvement in care

Existing legislation in Wales and England enshrines the involvement of individuals in decisions about their life. Legislation around capacity is currently being considered in Northern Ireland. Similarly, regulations across England, Wales and Northern Ireland strongly emphasise the importance of individuals being central to decisions about their care and their quality of life.

DEMFAM respondents strongly indicated that they felt it was important that the person with dementia was involved in decisions about their care (see Table 2.1).

Table 2.1 Importance of involving the person with dementia in decisions about their care

Survey	Important		Not Important		Neither important nor unimportant	Don't know/ didn't answer
	77% (882)		8% (93)			
DEMFAM	26% (301) quite important	51% (581) very important	5% (56) not very important	3% (37) not important at all	7% (76)	8% (88)

However, DEMFAM found considerable uncertainty from respondents regarding how well the home was performing in terms of involving the person with dementia in decisions about their care, but DEMSTAF respondents were more positive about engagement with people with dementia in the care homes they worked in (see Table 2.2).

Table 2.2 How the home was performing in relation to involving the person with dementia in decisions about their care

Survey	Positive		Negative		Satisfactory	Don't know/ didn't answer
	29% (329)		18% (204)			
DEMFAM	20% (224) good	9% (105) very good	10% (109) poor	8% (95) very poor	24% (268)	30% (338)
	59% (380)		9% (57)			
DEMSTAF	40% (26) good	19% (120) very good	7% (47) poor	2% (10) very poor	20% (184)	4% (26)

In the DEMSTAF survey, 82% of respondents (531) reported that reminiscence therapy or life history work was used in the home they worked in; 7% (44) said the home didn't use such tools and 11% (72) either didn't know or didn't respond.

Engaging and involving people with dementia in their own care is essential, and also a legal right. It is important that the care home sector seeks to demonstrate how they support people to be involved in decisions and promote this to service users, family members and others. Evidence from the CQC in England suggests that lack of person-centred planning was the most common issue where care homes were not meeting standards (CQC, 2012a). Regulations and sector and local quality improvement programmes should ensure that evidence of engagement with residents with dementia is at the heart of quality improvement in the care sector.

The Society believes that tools such as life history work, or our document **This is me**, are valuable mechanisms for promoting person-centred care and involving people with dementia in decisions about care, and should be used across the sector.

4.3.2.2 Staff understanding

Dementia is a complex condition and staff need knowledge – both about the impact of dementia and also around practical components of care – to deliver high-quality care to residents with the condition. Training and learning should not be a single event, but an ongoing process which focuses on embedding concepts in practice. Ensuring staff have sufficient knowledge and understanding of dementia faces a number of challenges. Staff turnover in many care homes is high, with some homes relying on agency staff. Wages for staff in care homes are low, and tight cost margins of the sector limit resources available for funding training and higher wages.

At present, there is no mandatory requirement for staff to undergo training on dementia care or on understanding the needs of people with dementia. In the Home from home report, the Society called for mandatory training on dementia for all staff working in care homes.

It is clear that DEMSTAF respondents find the provision of care to people with dementia challenging, underlining the importance of sufficient training (see Table 3).

Table 3 How challenging the provision of care to people with dementia is

Survey	Challenging		Not challenging		Don't know/ didn't answer
DEMSTAF	86% (554)		12% (76)		3% (17)
	57% (366) quite challenging	29% (188) very challenging	7% (43) not very challenging	5% (33) not challenging at all	

Results from DEMFAM and DEMSTAF indicate that many respondents felt positive about the training of staff and understanding of dementia. However, DEMSTAF respondents were biased towards those staff who had worked for small numbers of providers, which is not a true reflection of the care home workforce. This may have skewed results and may indicate that responses have come from better-performing homes (see Tables 4.1–4.4).

Table 4.1 Staff understanding of how to provide care for people with dementia

Survey	Positive	Negative	Satisfactory	Don't know/ didn't answer
DEMFAM	68% (766)	10% (115)	20% (223)	3% (35)
	36% (409) good	31% (357) very good		
DEMSTAF	74% (481)	4% (28)	20% (132)	1% (6)
	43% (281) good	31% (200) very good		

Table 4.2 Has enough training been received on delivering care to people with dementia?

Survey	Yes	No	To some extent	Don't know/ didn't answer
DEMSTAF	54% (348)	7% (47)	37% (237)	2% (15)

DEMSTAF respondents had positive views on the benefits of training to helping them provide care.

Table 4.3 Importance of training in helping to provide care to residents

Survey	Vital	Important	Not very important or of no use	Don't know/ didn't answer
DEMSTAF	50% (325)	41% (264)	3% (17)	6% (41)

DEMSTAF and DEMFAM respondents were also both very positive regarding the dignity and respect residents were treated with. DEMSTAF respondents were the more positive group, though this may well have been influenced by the sampling of the survey.

Table 4.4 Level of dignity and respect with which residents were treated

Survey	Positive		Negative		Satisfactory	Don't know/ didn't answer
DEMFAM	73% (827)		10% (115)		16% (185)	2% (28)
	34% (382) good	39% (445) very good	6% (65) poor	3% (34) very poor		
DEMSTAF	88% (567)		2% (11)		9% (60)	1% (9)
	37% (237) good	51% (330) very good	1% (7) poor	1% (4) very poor		

People with dementia responding to our short survey strongly said they felt well treated by staff; 91% (31) said they were well treated by staff and 9% (3) said sometimes.

These findings indicate positive views from respondents about the levels of training for staff. This is welcome, especially since – as evidenced by DEMSTAF findings and others – providing care to people with dementia is challenging and requires knowledge and understanding.

In a minority of homes, issues with workforce understanding, and provision and uptake of training remain widely reported. In England, the CQC's latest State of care report found significant numbers of care homes were not meeting standards on training: 24% of nursing homes were not meeting standards on training and supervision and 16% of residential homes were not meeting standards (CQC, 2012a). Issues with workforce understanding were identified in the National Assembly for Wales Health and Social Care Committee report (National Assembly for Wales Health and Social Care Committee, 2012).

The RCN's report, *Persistent challenges*, found that responses from nurses highlighted issues around funding for training, challenges with high turnover, and lack of staffing to cover staff going on training (RCN, 2011). For the **Home from home** survey, 46% of care home manager respondents stated that funding training was one of their top three biggest challenges (Alzheimer's Society, 2008a). The 2009 report of the APPG on Dementia, *Prepared to care*, found that the social care workforce was not equipped to meet the challenge of dementia (APPG on Dementia, 2009). Issues with training were also reported in the APPG's 2008 report on antipsychotic drugs in care homes, *Always a last resort* (APPG on Dementia, 2008), and CSCI's *See me, not just the dementia* (CSCI, 2008).

The Society believes that responsibility for ensuring the social care workforce has sufficient understanding of dementia lies with providers, regulators and local and national government. We reassert that learning on dementia should be mandatory for all care home staff. The Society believes that this could be achieved through workforce regulation, combined with stronger minimum standards from regulators and effective actions from local authorities to ensure provision of training to the local social care workforce. However, central government must recognise that appropriate levels of national funding must be put in place to ensure workforce understanding is improved across all homes, including ensuring agency staff receive training in high-quality dementia care.

4.3.2.4 Format and coverage of learning

There is considerable variety in the format and focus of training on dementia for care home staff. Many care home providers, especially larger ones, run in-house training programmes. In addition, a range of external training programmes exist, including Alzheimer's Society programmes. Other training systems include e-learning modules on dementia care, such as those produced by SCIE.

Through the DEMSTAF survey, the Society wanted to develop an understanding of the format of training provided to respondents

- Over three quarters of DEMSTAF respondents (77% – 495) said that the training they had received from their current employer was training with regular updates, with 13% (83) saying training was one-off, and 8% (51) saying they had not received any training; 3% (18) either did not respond or said they didn't know.
-

The most common form of training provided to staff was in-house training:

- three quarters of respondents (75% – 483) reported that they had received an in-house training course on dementia
- 60% (390) had learnt from working with more experienced staff
- 49% (314) said they had received another form of external training or course on dementia
- 38% (246) said they had an NVQ in dementia care
- 24% (156) had undergone e-learning.

Dementia training should be holistic and should cover a range of aspects of care provision, in both practical and personalised areas. When asked to assess whether they had received enough training in relation to certain areas of care, DEMSTAF respondents felt that staff had covered many areas in full. However, in relation to other areas of dementia care, smaller numbers of respondents reported that training had covered these areas in full (see Table 5.1).

Table 5.1 Training coverage of different areas of dementia care – DEMSTAF responses

Area	Training covered this area in full	Training covered this area a little	Training did not cover this area	Don't know/ didn't answer
Providing care which promotes dignity and respect	80% (518)	12% (79)	5% (31)	3% (19)
Providing personalised care	77% (495)	14% (93)	6% (37)	3% (22)
Toilet needs	75% (485)	16% (104)	5% (34)	4% (24)
Moving and handling people with dementia	73% (474)	17% (113)	6% (40)	3% (20)
Communicating with people with dementia	73% (473)	17% (111)	6% (37)	4% (26)

Table 5.1 Training coverage of different areas of dementia care – DEMSTAF responses (continued)

Area	Training covered this area in full	Training covered this area a little	Training did not cover this area	Don't know/ didn't answer
Suspected abuse of people with dementia	72% (463)	18% (119)	6% (39)	4% (26)
Understanding the difficulties people with dementia may face eating and drinking	68% (437)	23% (149)	6% (38)	4% (23)
Recognising symptoms of dementia	64% (413)	26% (169)	6% (40)	4% (25)
Responding to challenging behaviours	63% (409)	25% (161)	8% (52)	4% (25)
Emergency first aid training	59% (383)	21% (139)	14% (91)	5% (34)
Recognising pain in people with dementia	53% (346)	34% (221)	8% (52)	4% (28)
Use of antipsychotics and alternatives	40% (256)	33% (214)	17% (112)	10% (65)

Despite DEMSTAF respondents widely reporting that training had covered many areas of dementia care in full, many respondents still said they needed more training. In all areas listed except one – toilet needs – more than half of respondents said they needed a little or a lot more training.

In five specific areas of dementia care, a fifth or more respondents said they needed a lot more training. These are set out in Table 5.2.

Table 5.2 Areas where more training is needed – DEMSTAF responses

Area	A lot more training needed	A little more training needed
Responding to challenging behaviours	26% (160)	42% (273)
Use of antipsychotics and alternatives	26% (166)	44% (286)
Emergency first aid training	23% (150)	38% (247)
Recognising pain in people with dementia	22% (142)	46% (298)
Suspected abuse of people with dementia	20% (127)	39% (251)

Ensuring staff who provide care to people with dementia have sufficient knowledge and understanding is essential to the delivery of good care in care homes. Findings from our surveys suggest positive views on the provision of training to staff, although responses around what training DEMSTAF respondents had received were less positive than findings from **Home from home**, where 86% said they had received in-house training, 79% said they had learned from more experienced staff, and 69% reported they had received other external training (Alzheimer's Society, 2008a).

There remains a challenge to ensure that care home staff across the sector have the necessary skills to deliver good care to people with dementia. The Society reiterates its call from **Home from home**, that all staff working in care homes have mandatory, funded training on dementia. The Society believes that the government, working with Skills for Care and the Health and Care Professions Council, must show leadership in developing a system of workforce regulation of the care sector in order to ensure the entire care workforce have sufficient understanding and skills in providing dementia care. However, consideration needs to be given to how to meet the costs of this so that the burden is not placed on low-paid care staff.

In the interim, local authorities and national governments must work to improve workforce skills, including local authorities themselves mandating levels of dementia learning for care home staff. Local Dementia Action Alliance and emerging work on dementia-friendly communities should also prioritise and resource improving workforce understanding and find resources to enable this. The Dementia Care Compact in England could also be strengthened to require greater prioritisation of and investment in workforce understanding of dementia.

Furthermore, many staff continue to report that they want to receive more training on a range of areas, in spite of responding that the training they had received had covered these areas in full. The Society believes that training programmes and systems must be continuous, and should seek to embed best-practice dementia care within care homes and the care sector. We welcome some indication from DEMFAM and DEMSTAF that progress is being made on this front, but clearly in light of continued evidence of the need for more training and findings from this survey, more progress is needed.

Improving workforce understanding must also take into account provision of training on the use of antipsychotics and their alternatives. As the area where most DEMSTAF respondents said they needed more training, it is clear that gaps remain in current provision in training on this area.

4.3.3 Activities

The provision of meaningful occupation for people in care homes with dementia is an important tool to ensure both good quality of life and good care. Lack of occupation was one of the major findings from the Society's report, **Home from home**, and the importance of residents participating in meaningful activities is emphasised by literature reviews to inform the My home life project (Reed, 2007).

There is a wide and increasing range of interventions which can support people with dementia to remain occupied, either focused on the group or the individual. Which interventions are most effective or feasible will depend on factors such as the stage of dementia. Similarly, activities should be tailored to individual needs based on reminiscence or life history work, or informed by personal profiles such as the **This is me** tool. Provision of meaningful activities for people with dementia is a challenging and complex area. Provision of appropriate activities requires sufficient staffing to ensure that staff have time to engage people with dementia in services.

DEMFAM respondents strongly recognised the importance of remaining active (see Table 6.1).

Table 6.1 Importance of residents remaining active

Survey	Important	Not Important	Neither important nor unimportant	Don't know/ didn't answer
	92% (1,047)	2% (20)		
DEMFAM	20% (225) quite important	72% (822) very important	1% (10) not very important	1% (10) not important at all
			3% (34)	3% (37)

However, activities and occupation were one of the areas where DEMFAM respondents gave the least positive responses. Care home staff responding to DEMSTAF were more positive in their responses on this area (see Table 6.2).

Table 6.2 Opportunities for the person with dementia to be involved in activities in the care home

Survey	Positive	Negative	Satisfactory	Don't know/ didn't answer
	44% (501)	24% (267)		
DEMFAM	28% (316) good	16% (185) very good	16% (179) poor	8% (88) very poor
			25% (284)	8% (86)
	58% (375)	15% (94)		
DEMSTAF	37% (237) good	21% (138) very good	12% (75) poor	3% (19) very poor
			26% (171)	1% (7)

DEMSTAF found almost identical results for how staff rated the home relating to maintaining hobbies and interests (see Table 6.3).

Table 6.3 Ability to maintain hobbies and interests in the home

Survey	Positive		Negative		Satisfactory	Don't know/ didn't answer
	58% (374)		14% (88)			
DEMSTAF	37% (238) good	21% (136) very good	11% (73) poor	2% (15) very poor	26% (173)	2% (12)

Furthermore, as highlighted above, findings from DEMSTAF suggest high levels of reminiscence and life history work prevail, with 82% of respondents saying this took place in the home.

Just over two thirds of people with dementia responding to our short survey (68 –23) said they felt they had lots of things to keep them busy. 15% (five respondents), said they sometimes did and 15% (five respondents) said they did not. One respondent did not answer.

These results suggest that provision of activities and occupation in care homes remains an issue, although some improvement may have been made since **Home from home**, when 54% of respondents told us their relative did not have enough to do.

Many in the care sector maintain that meaningful occupation does not necessarily mean structured activities. The Society agrees, but our DEMFAM findings suggest a lack of faith from family members that people with dementia have activities to be involved with. The care sector must do more to raise awareness of how it keeps residents occupied and active, and how occupation in care homes can be structured.

Activities and occupation should be more than simply structured group sessions at set times; they should involve providing individual residents with choices and tailored activities focused on individual's needs and preferences. Meaningful occupation can include participation in domestic activities, such as cooking or other household chores.

The Society believes that staffing levels in care homes should allow staff sufficient time to provide activities. Concerns continue to be expressed that staffing levels are insufficient to allow best-practice care, despite evidence that interaction with residents is important to staff. Care homes should also seek greater involvement of volunteers to support the provision of activities within homes, and government should look at regulation and guidance to enable this.

The high levels of reported use of reminiscence therapy or life history work from DEMSTAF is welcome, though it should be reiterated this is a self-selecting sample. Government, regulators and the care home sector have a responsibility to do more to promote these. The sector also needs to work with staff and family to raise awareness of the importance of occupation in its broader sense and support family and residents to complete the document **This is me**, or other personal profile tools.

4.4 Abuse and infringement of mental capacity legislation

Incidences of abuse and infringement of capacity can have devastating implications for individuals, and can be incredibly distressing for family and loved ones. They also act to damage severely the reputation of the care sector, raising the spectre of unseen and unknown levels of abuse taking place.

The symptoms of dementia put people living with the condition at particular risk of abuse, since they may be unable to report that they have been victims of abuse. Poor care can also be harmful to people with dementia, who may be unable to express preferences about what they want. Staff without sufficient knowledge or understanding may respond inappropriately or in a harmful way to behavioural and psychological symptoms of dementia, which may be indications of underlying pain, distress or need.

The issue of abuse in care homes is one which has received significant attention in light of high-profile incidences reported in the media. While such cases have not exclusively involved people with dementia, they have served to undermine public faith in the delivery of high-quality care to people with dementia in care homes. Protections from abuse exist in a number of forms, including regulatory standards, criminal law and protection from deprivation of liberty under the Mental Capacity Act 2005. Similarly, care homes should have internal complaint procedures and training in place for staff.

Findings from our YouGov poll of UK adults demonstrate the significant public concern around abuse. As outlined above, 70% of UK adults said they would be scared of moving into a care home in the future. When asked what their biggest concern would be about a relative going into a care home, over a half of UK adults (53%) said it would be of their relative being abused. Responses to this question in full were:

- 53% said the risk of their relative being abused
 - 18% said risk of their relative losing their independence
 - 12% said lack of activities for their relative/boredom
 - 6% said that they would have less influence over decisions about their care
 - 2% said risk that the home would be closed
 - 1% said another concern not listed
 - 8% didn't know.
-

When asked if the care home sector wasn't doing enough to prevent abuse of older people in care homes, UK adults responding to our YouGov public poll strongly stated they agreed homes were not doing enough:

- 64% agreed the care home sector was not doing enough to prevent abuse of older people in care homes (27% strongly agreed, 37% tended to agree)
- 19% neither agreed nor disagreed
- only 7% disagreed that the care home sector was not doing enough to prevent abuse of older people in care homes (2% strongly agreed, 5% tended to agree)
- 10% didn't know.

The Society did not seek to gather evidence about abuse in our DEMFAM survey, but did ask care home staff about training around suspected abuse of people with dementia.

- As highlighted above, 72% of DEMSTAF respondents (463) felt that the training they had received fully covered suspected abuse of people with dementia.
- 20% (127) felt they needed a lot more training on this area; 39% (251) said they needed a little more training on this area.

Evidence from our YouGov public poll of UK adults underlines that abuse is the major concern for the public around care homes, and that the care home sector is seen as not doing enough to prevent abuse of older people. While this report has found many positive findings relating to views on care, the sector must respond to the public perception of abuse. Individual providers have a duty to stamp out abuse, and the sector must condemn abuse where it is found. The Society does not believe the public will develop faith in the care home sector unless the sector is seen to be leading the fight against abuse.

Abuse and infringement of mental capacity in care homes are closely linked to appropriate regulation and training, something which is recognised by Action on Elder Abuse (Action on Elder Abuse [online]). Appropriate provision of training, and systems to ensure training is adapted into practice, can help to ensure staff have the skills and understanding to respond to the needs of people with dementia, rather than responding inappropriately to behavioural symptoms in ways which infringe people's rights. Appropriate training can also help staff to identify abuse by other staff or professionals. It is welcome that responses from our survey were positive in this regard, although it is clear from DEMSTAF that many staff responding still felt they needed more training in this area.

Regulators and safeguarding teams based in local authorities and trusts must also take swift action where incidences of abuse are reported. It is insufficient for issues as grave as abuse or breach of mental capacity to be considered as part of a general complaints procedure. The Society believes regulators have a responsibility to act as a first port of call for such complaints, and we welcome the establishment of clear guidance from the CQC for providers and staff on whistleblowing. In addition, we believe that adult safeguarding boards should be involved and engaged with regulators to share information. Northern Ireland should bring forward legislation to protect people's capacity.

4.5 Recommendations

Recommendation 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.

Recommendation 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 fear 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 home 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.

Case study 2

Positively Enriching and enhancing Residents' Lives (PEARL) Programme

Four Seasons Health Care – 56 accredited homes across the UK and a further 70 homes in process

Project description

The PEARL programme was developed in 2008 to help homes to become 'specialist dementia care units'. There are 155 criteria against which homes work towards achieving a score of 5 (excellent, happening all of the time), and which are based on evidence and research-based practice. Each home has a dedicated dementia care project manager, who helps them to carry out their baseline and to identify areas that need to develop. Within the 12-month period, staff will undertake person-centred care training and resident experience training, and some are also trained in the use of University of Bradford's dementia care mapping. The main areas in the programme are as follows:

- life story work (and incorporating into daily life and documentation)
- enhancing the environment (to reduce distress and promote orientation and inclusion)
- activity and engagement (using life story work)

- positive approaches to health and well-being (identifying and reducing pain, reducing use of antipsychotics, identifying and reducing depression, increasing weight)
- a person-centred and inclusive environment (both residents and staff)
- knowledgeable staff
- proactive staff and management.

Homes are validated by members of the Dementia Care Team when both the home manager and project manager feel that they are ready, but this visit is unannounced. Homes need to achieve at least 65% of score 5 to gain PEARL accreditation at Bronze level, but most homes have Silver (75%) or Gold (85%) awards, and one home has a Platinum award (95% of criteria at score 5).

Following validation, homes continue to receive a support visit from their project manager every three months until revalidation.

Why it was needed

Many of the homes were providing great fundamental care. People had all their basic human needs met and staff were very caring. But, initially, there were a lot of distressed reactions, as some of the staff in the homes did not always understand the specific needs of a person living with dementia and/or the resources available that might help to reduce their distress, eg appropriate signage, doll therapy, reduction of antipsychotic medication (rather than an increase) to name but a few.

Some staff were initially quite sceptical until they were able to see for themselves that certain interventions would work (eg doll therapy, validation therapy), but for the most part, staff have fully embraced the ideas in the programme and developed their own micro-projects to achieve the required standard.

Impact and feedback

The PEARL programme has been a phenomenal success, without exception. There has been an overall reduction in antipsychotic use by an average of 50% across the homes validated. There have been significant reductions in falls, dependency and distress reactions, and increases in weight and activity.

Staff are extremely emotional when they achieve their award and feel proud of their PEARL status and their specialist knowledge. Relatives have spoken to Four Seasons and told them about the difference the programme has made. For one lady, the experience with her husband was literally life-changing.

The PEARL programme has won several awards and been highly commended for many others over the past four years.

Case study 3

Worcestershire dementia care training and development programme

Project description

The Worcestershire care home programme commenced as a pilot in 2009/10, and has run as a full programme since 2010/11. The aim of the programme is to support care homes to improve the quality of care provided to residents with dementia.

The programme is based around supporting care homes to meet Worcestershire's person-centred dementia care standard, which is based on the Dementia Matters 50-point checklist. Care home providers undergo a three-tiered training programme and are subsequently assessed against the standard. The programme consists of the following courses:

- leadership – inspiring leadership for senior managers or owners (five days)
- specialist – supporting change among front-line staff (10 days)
- good practice – understanding and applying person centred dementia care (two days).

Care homes meeting the standard are awarded a dementia reward grant. Those not meeting the standard are provided with advice and support around how they can improve to meet the standard in the future. Care homes can opt to be assessed against the standard without going through the training programme, but if they do not meet the standard must go through the training programme prior to any future assessment.

Why it was needed

Worcestershire County Council developed the programme as a means of assessing the performance of care homes in their area and supporting improvements to the quality of dementia care in Worcestershire care homes. Worcester wanted to acknowledge those homes which were providing excellent dementia care and differentiate these homes from those where further improvement was still needed.

Impact and feedback

As of January 2012, 46 homes had passed the standard (in part or fully) and it was projected that by the end of 2012/13, a total of 55 homes would have passed the standard, representing over one third of care homes in the county (residential and nursing). The courses delivered for the specified number of care home staff over the course of the programme are outlined in the table opposite.

Courses delivered during Worcestershire dementia care training and development programme

Course name	Number of courses run	Staff attendance
Leadership	7	103
Specialist	10	192
Good practice	36	696

The vast majority of attendees have indicated that, overall, the courses have been good or excellent, and that they are likely or highly likely to have a positive impact on their work practice. This has been borne out by the observed improvements in care practice and the subsequent number of care homes passing the dementia standard. Examples of innovative improvements that go beyond more fundamental enhancements in the quality of care include the creation of memory walls, reminiscence DVDs, the wearing of nightwear during night shifts, and generally making homes more vibrant and active.

A survey in early 2012 also identified that 100% of those who attended leadership courses would recommend them to colleagues. In 2011, a family and carer survey of approximately 70 people evidenced a high degree of satisfaction with all aspects of care provided at care homes, based on questions built around the Worcestershire dementia standard.

5 Community

Summary

- 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 of 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.

5.1 Introduction

Ensuring people with dementia can enjoy a good quality of life in care homes requires more than simply the delivery of good care. External health and care services, as well as involvement of volunteers and others, are important components to ensuring people with dementia are supported in their homes.

This chapter will look at findings from our surveys around access and quality of external services delivered from outside the home, as well as findings around how the home works with the wider community.

5.2 Working with health services

People with dementia are likely to have significant health needs, as a result of their dementia, but also because of possible additional comorbidities. Access to and support from general practice and other health services are therefore essential.

Many people with dementia in care homes are likely also to be using prescription medicine, either for their dementia or for another health issue, the use of which requires monitoring. The pharmacy sector has engaged strongly with the appropriate prescriptions of medicines, including supporting a review of antipsychotics, which, despite reductions in prescriptions, are still too often inappropriately prescribed to people with dementia in care homes.

- 20% of DEMFAM respondents (224) said the person with dementia was prescribed antipsychotics; 64% (730) said they were not prescribed antipsychotics and 16% (185) said they didn't know.

Findings from DEMFAM and DEMSTAF suggest that there are positive views on access and support from general practice (see Tables 7.1 and 7.2).

Table 7.1 Access to and support from general practice for the person with dementia – DEMFAM

Positive		Negative		Satisfactory	Don't know/ didn't answer
56% (637)		12% (137)		23% (257)	9% (107)
28% (318) good	28% (319) very good	8% (85) poor	5% (52) very poor		

Table 7.2 Does the person with dementia get enough support from general practice? – DEMSTAF

Yes	To some extent	No	Don't know/ didn't answer
55% (354)	29% (190)	12% (78)	4% (25)

When asked views on support from other health services, both groups were less positive (see Tables 8.1 and 8.2).

Table 8.1 Access to and support from other health services for the person with dementia – DEMFAM

Positive		Negative		Satisfactory	Don't know/ didn't answer
36% (408)		18% (200)		19% (214)	28% (317)
23% (257) good	13% (151) very good	11% (125) poor	7% (75) very poor		

Table 8.2 Does the person with dementia get enough support from other health services? – DEMSTAF

Yes	To some extent	No	Don't know/ didn't answer
43% (281)	36% (232)	14% (90)	7% (44)

The findings from these surveys indicate broadly positive views on links with general practice, although there remains room for improvement, and respondents were less clear around quality and access to other health services. Positive findings on working with general practice are to be welcomed, especially since this is an area where issues and challenges have been identified. The literature review to inform My home life found that access to GP services can be problematic and that specialist mental health services were not widely available (Heath, 2007). Issues with lack of access and support from health sectors was also identified by nursing working in care homes in the RCN report, Persistent challenges (RCN, 2011)

Data from the CQC in England has demonstrated ongoing issues with access to health services in care homes. A study by the British Geriatrics Society (BGS) looking at CQC data published in March 2012 outlined that many primary care trusts lacked targets to ensure residents in care homes had access to assessments and health services (BGS, 2012; CQC, 2012b). In England, the NHS Atlas of variation in healthcare showed significant variation in admission rates from care homes to hospitals, indicating significant variation in services to reduce avoidable admissions (NHS Right care, 2011). Evidence on residential care presented to the National Assembly for Wales Health and Social Care Committee outlined challenges with working between health services and care homes (National Assembly for Wales Health and Social Care Committee, 2012).

The way care homes contract with GP services has also been identified as a challenge. There is considerable variation in the contracting arrangements between GP services and care homes. In some instances care homes have to contract and pay for GP services for residents. A CQC review of healthcare services in care homes found that 10% of care homes said they paid for GP services (CQC, 2012b).

The Society strongly condemns forcing residents with dementia to pay for access to GP services that they would receive without charge in their own home. This is contrary to the principles of the NHS, and is burdening people often already paying large sums of money for care with additional charges. The NHS Commissioning Board, the NHS in Wales and the DHSSPS in Northern Ireland must make funds available to ensure GP services and clinical commissioning groups have resources to deliver services to people in care homes. The Society calls on regulators, including Monitor in England, to review this practice as a matter of urgency. Care homes should refuse to pay such charges and report to regulators any GP surgeries levying them.

More broadly, commissioners of health services must ensure that people with dementia living in care homes have the same access to health services as they would living in the community. Care assessment and planning must be conducted between health and care services, and should include regular review.

The Society believes that service planning and needs assessments, such as joint strategic needs assessments in England, must include assessment and projection of numbers of people living in care homes and potential needs. Commissioners and service planners must put resources in place to meet these needs.

5.2.1 Access to dentists

Access to good dental services is important to both the health and quality of life of people with dementia. Poor dental health can lead to other health complications, as well as being distressing for residents, which can lead to pain-related behaviours that staff may struggle to respond to. Arranging dental care, especially more complex procedures, for people with dementia in care homes, can be challenging.

DEMFAM found that large numbers of respondents didn't know about the access and support of dental services (see Table 9.1).

Table 9.1 Access to and support from dental services for the person with dementia – DEMFAM

Positive		Negative		Satisfactory	Don't know/ didn't answer
23% (259)		19% (220)		18% (200)	40% (460)
14% (154) good	9% (105) very good	9% (104) poor	10% (116) very poor		

DEMSTAF respondents were broadly positive about support from dentists to residents with dementia (see Table 9.2).

Table 9.2 Does the person with dementia get enough support from dentists? – DEMSTAF

Yes	To some extent	No	Don't know/ didn't answer
44% (286)	34% (223)	15% (99)	6% (39)

A report from the British Dental Association (BDA) identified that access to good dental care in care homes varied. They identified that in some cases dental treatment was reactive and only took place when things went wrong, whereas in other homes provision of dental services was good. The BDA highlighted issues with lack of communication between commissioners and providers (BDA, 2012). Others have criticised those providing dental services for a lack of understanding of dementia and the needs of those affected. The need for access to dental care for residents in care homes was recognised in the National Assembly for Wales Health and Social Care Committee report on residential care (National Assembly for Wales Health and Social Care Committee, 2012).

Inspections of care homes should seek to determine the state of access to dental services, and regulation of dental services should consider provision of services to care homes, where appropriate. Commissioners and service planners must ensure that dental services for people with dementia in care homes are in place.

5.3 Volunteers and community

Care homes should not be isolated venues of care provision, but actively engaged with the wider community. Alongside health and care services for residents, working with friends, family or volunteers can play a crucial role in ensuring people can enjoy a good quality of life. Furthermore, where possible, people with dementia can benefit from trips, arranged either through the home or by friends and family.

DEMFAM respondents provided mixed responses on how homes were performing on these areas (see Table 10.1).

Table 10.1 Involving friends, family and volunteers – DEMFAM

Category	Positive		Negative		Satisfactory	Don't know/ didn't answer
Volunteers coming into the home	28% (315)		22% (249)		18% (206)	32% (369)
	18% (204) good	10% (111) very good	12% (131) poor	10% (118) very poor		
Opportunities for trips out of the home	26% (301)		31% (354)		22% (256)	20% (228)
	18% (209) good	8% (92) very good	16% (182) poor	15% (172) very poor		

Table 10.1 Maintaining links with friends, family and volunteers – DEMFAM

Category	Positive		Negative		Satisfactory	Don't know/ didn't answer
	55% (630)		11% (126)			
Involving friends or family in decisions about care	26% (297) good	29% (333) very good	8% (87) poor	3% (39) very poor	22% (255)	11% (128)

DEMSTAF respondents were even more positive on how the home was performing in relation to involving friends and family (see Table 10.2).

Table 10.2 Involving friends and family of residents with dementia – DEMSTAF

Positive		Negative		Satisfactory	Don't know/ didn't answer
80% (516)		4% (28)			
36% (232) good	44% (284) very good	3% (20) poor	1% (8) very poor	14% (91)	2% (12)

Findings on involving friends and family may suggest that there has been progress since the report **Home from home**, which found that 22% of respondents were unsatisfied with the level of their involvement in decision-making, and 29% felt they didn't receive enough information and updates about care. While not directly comparable, only 11% of DEMFAM respondents said the home was poor, indicating a more positive response.

The ILC report, *Care home sweet home*, outlined that volunteers can provide crucial support and much-needed services in care homes. However, participants at the workshops to inform the report outlined that they had concerns with recruiting volunteers and creating an environment for attracting and retaining volunteers. The ILC report also called for greater engagement between care homes and the community (Mason, 2012).

Volunteers can play a key role in ensuring people with dementia living in care homes can enjoy a good quality of life, with opportunities for social interaction and occupation. Adequate procedures should be in place to facilitate volunteer involvement and engagement in care homes, while ensuring that appropriate checks are in place to safeguard residents, supported by regulators and safeguarding teams. Consideration should be given to how local and national guidance and regulations can promote volunteering in care homes.

Initiatives such as Dementia Friends could potentially provide a base of volunteers interested in working in care homes. This is an Alzheimer's Society initiative to improve public knowledge about dementia, which aims to reach 1 million people by 2015. For more information visit dementiafriends.org.uk. Care homes and patient organisations should explore means of supporting volunteering and encouraging friends and relatives of homes to play a role volunteering with homes.

The Society recognises that, with increasing dependency, organising trips for people with dementia outside the home can be a challenge. However, the Society believes that efforts should be made by homes to engage with positive risk-taking around trips out of the home, especially in residential care.

More broadly, Alzheimer's Society believes that care homes, with their expertise in dementia, can play a crucial role in supporting the development of dementia-friendly and supportive communities. The Society calls on the sector to engage with the dementia-friendly communities programme and to put itself forward as a key partner in supporting local action. This is likely to be crucial to raising public faith in the sector and its work.

5.4 Dementia care in specific groups

The focus of this report has been on the evidence gathered from our surveys. However, specific groups of people with dementia face issues and challenges not covered in our surveys. Some general remarks on these have been made below.

5.4.1 People with learning disabilities

As highlighted above, the Society believes there is likely to be a growing issue with support for people with learning disabilities and dementia living in care homes. As increasing numbers of people with learning disabilities reach older age, rates of dementia among this group are likely to increase. This will pose challenges, both for people with learning disabilities living in care homes, and for those living in the community but who may need to go into a care home as a result of increasing need. Sharing of understanding between specialist care homes for people with learning disabilities, and dementia care homes, could help to ensure that both sides of the workforce develop sufficient understanding.

5.4.2 Younger people with dementia

Younger people with dementia face specific challenges in terms of finding appropriate care home services. They may be more physically able and so be more prone to certain behavioural symptoms of dementia, such as walking about, or may need staff to be more careful when responding to symptoms such as aggression.

The Society knows that some care homes operate minimum age policies, which act as a barrier to younger people with dementia. However, in other instances we have heard of younger people with dementia struggling to cope when admitted to homes where activities are designed around older adults. Local authorities should ensure that local care home markets have the capacity and skills to meet the needs of younger people with dementia.

5.4.3 People with dementia from black, Asian and minority ethnic groups

In 2007, an Alzheimer's Society report, Dementia UK, estimated that there were 11,000 people from black, Asian and minority ethnic (BAME) groups living with dementia in the UK. It is likely that this figure has risen significantly since, and will continue to rise in coming years. The 2011 UK census found 14% of the UK population identified with an ethnic group other than white and that this had risen significantly over recent years.

How care home services cater for the needs of people with dementia from BAME communities is likely to be dependent on the needs of the individual, as well as on local demographics. The Society believes that the need for local care services to respond to needs of BAME groups should be recognised in joint strategic needs assessments in England and equivalents in Wales and Northern Ireland. At the time of writing, the APPG on Dementia is conducting an inquiry into services for people from BAME groups, the findings of which will be valuable for supporting care homes working with people from BAME communities.

5.4.4 People with dementia at end of life

The Society's report on end of life care and dementia, My life until the end, presented qualitative evidence on end of life care for people with dementia, including in care homes. The report identified that many participants in research said initial conversations about end of life care in care homes were handled poorly, and called for greater training of staff in initiating such discussions.

My life until the end found mixed experiences of people dying in care homes. While some relatives reported very positive experiences, others did not. The report identified challenges in end of life care in care homes, including lack of staff training in end of life care specialties, lack of access to specialist end of life care services such as support from hospices or palliative care, and inappropriate hospitalisation of people at the end of life (Alzheimer's Society, 2012b).

5.5 Commissioning, contracting and quality improvement

While local authority provision of care home services has fallen dramatically, and many residents are now part or full self-funders, local authorities have a vital role in the commissioning and contracting of care homes (except in Northern Ireland, where responsibility lies with health and social care trusts). Local authorities and trusts in Northern Ireland also have wider responsibilities for residents in care homes on safeguarding and workforce development.

The findings of this report, while suggesting broad satisfaction, and in many places high rating of care in care homes, indicate that more needs to be done, both to drive up quality and to eliminate failings of practice. Furthermore, as outlined above, regulators remain focused on compliance, rather than on quality improvement. Given their roles in contracting, commissioning and wider responsibilities, local authorities and trusts in Northern Ireland have a crucial role to play in quality improvement.

Local authorities have contracts in place with care homes where the costs of people with dementia are part or fully funded by the authority. The Society has reviewed a small number of these contracts to inform this report. Many elements of contracting, and also of commissioning plans, focus on procedural elements or reiterate aspects of regulations. While the Society believes these have a role, it is important that contracting and commissioning also identify and promote quality improvement.

Contracting and commissioning should encourage care homes to go beyond compliance with regulations, and focus on best-practice care. Contracting and commissioning should promote workforce development and encourage homes to engage with sector improvement mechanisms, such as My home life, or the Dementia Care Compact. Commissioning and contracting should also be used to encourage workforce development, setting higher standards, for example around minimum training on dementia, encouraging homes to undergo programmes such as Alzheimer's Society dementia champions, or the University of Bradford's dementia care mapping. The Society believes the advice provided in our contracting guide remains valuable to commissioners wishing to improve dementia care in care homes (Alzheimer's Society, [2010]).

The Society, in its consultation response to the CQC's 2013–16 strategy, highlighted the potential value in the development of a form of lay monitoring of care providers (Alzheimer's Society, 2012). In several areas, such systems have been developed or are in development. We believe lay monitoring of care homes would be valuable in terms of improving care and identifying challenges, but also in fostering engagement between communities and care homes. Continued local development of such models and national leadership on this issue should take place.

There is currently significant pressure on local and central government finances, as well as concerns relating to the financial viability of some care homes and care home companies. While the Society recognises this, failure to invest in quality is unsustainable. Proposals to cap costs of care and raise the means-tested threshold are welcome. The cap should be kept under review. Furthermore, the social care system remains chronically underfunded. Further resources are urgently needed to fill the funding gap.

5.6 Recommendations

Recommendation 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.
- The NHS Commissioning Board, 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 services.

Recommendation 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, and 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.

Case study 4

Dignity in Care Champions pilot – London Borough of Merton

Project description

The Dignity in Care Champions pilot was initiated by the Merton Seniors group in the London Borough of Merton. The purpose of the project will be to pilot a scheme delivered by volunteers to visit care homes used by the local authority within Merton, and possibly in neighbouring areas. At time of writing, the pilot is in very early stages. It is expected the pilot will run for 12–15 months.

The Merton Seniors successfully bid to Comic Relief for funding to undertake a feasibility project exploring the viability of having volunteers (lay assessors) to visit homes to speak with residents and to view the services and facilities delivered.

The feasibility study discovered that the boroughs of Lewisham and Southwark have similar schemes running effectively. The study also found that it would be possible to develop a scheme within Merton with the cooperation of London Borough of Merton and the care homes, with funding to set up the project and to recruit, train and support volunteers. A further bid was made to Comic Relief for funding to develop a pilot scheme to deliver project which was successful.

Why the project was needed

The Dignity in Care Champions pilot is borne out of concerns that Merton Seniors had about the lack of dignity, care and advocacy that residents in care and nursing homes experienced. They were also concerned about how funding cuts would affect the service delivered and increasing number of safeguarding concerns both locally and nationally.

Feedback and outcomes

The project is only in its initial stages, but it is hoped that volunteers will speak with residents about the service they receive and to look at facilities and activities delivered. The volunteers will prepare reports which will be given to the local authority and to the homes. Volunteers will also immediately raise any concerns around safeguarding, and make homes aware of information about activities and events in Merton.

A number of challenges to the pilot have been identified, which Merton will seek to overcome as the project progresses:

- getting the homes to work with lay assessors; the selling point to them would be a quality assurance for residents and the ability to advertise this on their literature/website
- ensuring the information/reports are acted on by the interested parties
- recruiting the volunteers with skills to be dignity in care champions.

Case study 5

Peterborough collaboration improves end-of-life care

Project description

The Gables is a Bupa specialist dementia nursing home in Cambridgeshire that works closely with the local healthcare community, particularly general practice, to improve end-of-life care for residents with dementia.

Working with the Peterborough Palliative Care in Dementia Group, The Gables has piloted a new approach to keep residents in the home at the ends of their lives, with proactive case management from a named GP.

A range of tools, protocols and supporting documents have been developed by the group to support this approach. The most recent initiative is a RICH (remain in care home) plan.

Why it was needed

The RICH plan works alongside the admission booklet, advance care plan and natural death form, to guide (and record) the family's wishes and, wherever possible, the resident's wishes, about end-of-life decisions. The RICH plan formalises the collective agreement between the GP, carers and the family, that remaining in the care home is in the resident's best interests, rather than an acute hospital setting which can cause severe distress.

This close working is mirrored on a practical level with weekly GP visits, working with the care team, and an open door for families to attend, so the GP can see the family together.

Feedback and outcomes

According to the home manager, Dawn Harbour, who sits on the Peterborough Palliative Care in Dementia Group, the approach has given staff the confidence to advocate, with the support of the resident's family and GP. Following a successful pilot, and the backing of NHS Peterborough, the project is being rolled out across all Peterborough care homes.

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Appendix A

Care home survey demographics and background statistics

Alzheimer's Society's care home report was based on three surveys of care home staff, people with dementia and family members of people with dementia living in care homes.

This appendix sets out the demographic and other statistics regarding those who responded to the surveys of family members (DEMFAM) and staff working in care homes (DEMSTAF).

Table A.1 Survey of family members of people with dementia (DEMFAM) – total respondents: 1,139

Who respondents were	
Family member of a person with dementia living in care homes	67% (765)
Family member of a person with dementia who used to live in a care home, but who no longer does	31% (350)
Person with dementia living in a care home	<1% (4)
Other	1% (6)
Not stated	1% (14)
Age of person with dementia	
0–40	0% (0)
40–64	3% (35)
65–69	6% (71)
70–79	26% (293)
80–89	46% (521)
90+	17% (192)
Not stated	2% (21)

Table A.1 Survey of family members of people with dementia (DEMFAM) – total respondents: 1,139 (continued)

How long has the person with dementia has had a diagnosis?	
less than 6 months	1% (13)
7–12 months	2% (22)
1–2 years	8% (96)
3–5 years	30% (346)
6–8 years	27% (303)
9–11 years	18% (208)
12–14 years	6% (70)
15+ years	4% (40)
Does not have a diagnosis	2% (23)
Not stated	2% (18)
Where was the care home the person with dementia lived in?	
England	92% (1,052)
Wales	4% (43)
Northern Ireland	3% (33)
Channel Islands	<1% (1)
Isle of Man	<1% (2)
Not stated	1% (8)

How long has the person with dementia lived in a care home?

< 6 months	15% (171)
7–12 months	14% (165)
1–2 years	27% (304)
3–5 years	29% (327)
6–8 years	10% (115)
9–11 years	3% (30)
12–14 years	1% (9)
15+ years	<1% (4)
Not stated	1% (14)

What type of care home was the person with dementia living in?

Nursing care home	42% (479)
Residential care home	38% (430)
Elderly and mentally infirm care home	24% (277)
Other care home	<1% (5)
Don't know	2% (25)

Did the care home say it was a dementia specialist care home?

Yes	71% (807)
No	19% (214)
Don't know	10% (118)

Table A.1 Survey of family members of people with dementia (DEMFAM) – total respondents: 1,139 (continued)

How much in total does the person with dementia/their family pay in care home fees per week?	
Does not pay	22% (250)
<£250	18% (208)
£250–£500	16% (183)
£501–£750	22% (245)
£751–£1,000	14% (163)
£1001–£1,250	3% (33)
£1251–£1,500	1% (12)
£1500+	1% (9)
Not stated	3% (36)
Is this good value for money?	
Yes	51% (585)
No	21% (235)
Don't know	28% (319)

Table A.2 Staff working in care homes (DEMSTAF) Total responses: 647

Who respondents were	
Care worker	54% (351)
Care home manager	10% (65)
Care supervisor / team leader / deputy manager	15% (95)
Registered nurse	11% (70)
Other	13% (82)
Not stated	1% (4)
What type of home staff respondents worked in	
Residential care home for elderly people	39% (254)
Registered dementia care home	46% (299)
Nursing home for elderly people	29% (188)
Don't know	<1% (2)
Other	<1% (1)
Not stated	3% (19)
Where in the UK staff respondents worked	
England	82% (532)
Wales	10% (67)
Northern Ireland	7% (43)
Channel Islands	0% (0)
Isle of Man	0% (0)
Not stated	1% (5)

Table A.2 Staff working in care homes (DEMSTAF) Total responses: 647 (continued)

How long staff respondents had worked caring for people in care homes	
<1 year	8% (49)
1–2 years	15% (94)
3–5 years	19% (122)
6–8 years	11% (72)
9–11 years	12% (79)
12–14 years	8% (49)
15+ years	27% (175)
not stated	1% (7)
How many care homes staff respondents had worked in over this time	
1	46% (297)
2	20% (128)
3	10% (63)
4	5% (34)
5	3% (17)
6	2% (12)
7	1% (4)
8	1% (3)
9	0% (0)
10	1% (4)
None	1% (8)
10+	<1% (2)
Not stated	12% (75)

Table A.2 Staff working in care homes (DEMSTAF) Total responses: 647 (continued)

How long staff respondents had worked in the home they currently work in	
<3 months	4% (26)
4–6 months	6% (39)
7–12 months	7% (48)
1–2 years	21% (136)
3–5 years	23% (151)
6–8 years	12% (77)
9–11 years	9% (58)
12–14 years	6% (42)
15+ years or longer	10% (62)
Not stated	1% (8)
Did staff respondents care for a close friend or relative who has dementia or another long term health or care need?	
Yes, I care for a family member or friend who has dementia.	9% (55)
Yes, I care for a family member or friend who has another long-term health or care need.	18% (117)
No, I don't care for a family member of friend.	74% (477)
Not stated	2% (12)

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:

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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](https://www.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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