Commission for Social Care Inspection

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Making Social Care Better for People

See me, not just the dementia

Understanding people's experiences of living in a care home

June 2008

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The Commission for Social Care Inspection aims to:

- put the people who use social care first
- improve services and stamp out bad practice
- be an expert voice on social care
- practise what we preach in our own organisation.

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Short Observational Framework for Inspection (SOFI)

Contents

Foreword

The Commission for Social Care Inspection has been seeking better ways of assessing the care of people with dementia, particularly the innovative models that are beginning to emerge. We were keen to understand the use of Dementia Care Mapping, a very powerful approach that can support truly individualised care. We sought advice from experts in the field of dementia care and teamed up with The University of Bradford to develop an observational tool for use by our inspectors.

SOFI (Short Observational Framework for Inspection) is a unique tool for inspectors, at the leading edge both in this country and internationally, and captures in a systematic way the experience of care by people who have great difficulties in communicating their feelings and views. By looking in detail at people's emotional well-being, who and what they are engaged with during the day, and how staff relate to them allows us to get beyond the surface of routine care practice. SOFI can reveal care that provides maximum dignity and respect to individuals.

SOFI is a methodology still under development but it is helping to raise the bar and drive improvements in the quality of care for people with dementia. Those who are doing well in providing care and support are now challenged to do even better, and to provide the truly personalised care that the recent multi-agency concordat to transform adult social care, *Putting People First*, seeks.

Dame Denise Platt DBE
Chair
Commission for Social Care Inspection

Introduction

> *'Once you've met one person with dementia...you've met one person with dementia.'*[1]

This report looks at the experiences of people with dementia living in care homes in England, with a particular focus on whether their care offers dignity and respect. Most similar studies have relied on the views of carers, care staff and people in the early stages of dementia. This study examines directly the experiences of people including those with advanced dementia.

Experiences of dementia

Dementia affects people in different ways. It often begins with short-term memory problems, confusion and anxiety. It is a progressive condition and is usually accompanied by increasing need for assistance with everyday activities and self-care. People may also experience distress, anger or depression which may be attributed to frustration with the effect of the illness on their lives. In the later stages people with dementia may not recognise familiar people or surroundings; they may become increasingly frail and may have difficulties caring for themselves, reasoning and communicating with others.

People may also experience shame or embarrassment, believing that they have in some way let themselves down because they can no longer undertake activities that they previously took for granted. Most people living with dementia want to continue

1 Quotation attributed to the late Tom Kitwood.

to do as much for themselves for as long as they can. This requires a careful and sensitive approach to the provision of care.

About this study

This study is based on findings of 100 full thematic inspections which involved examining directly the experiences of people with dementia and:

- gathering information about the home before the visit
- speaking with people living in the homes and their visitors
- talking with care staff and managers
- reviewing policies and procedures, including each home's statement of purpose, privacy and dignity policies and staff training records
- reviewing care plans
- observing practice using a new inspection tool, the Short Observational Framework for Inspection (SOFI) that has been developed better to understand people's experiences.

The inspections were guided by a series of key questions pertinent to people's dignity and respect:

- Are my wishes respected and my views taken into account?
- How am I treated and how do staff communicate with me?
- Do I have opportunities to relate to other people that are important to me?

About the organisations and people involved

One hundred care homes were chosen from each of the seven CSCI regions across England to reflect a broad range of care home characteristics (see Table 1 at the end of this introduction). Special attention was paid to include homes that provide care for different cultural and ethnic groups. We excluded homes that were subject to enforcement action[2] and homes that had received a key inspection within the last two months. So it is important to note that we had a sample with a large number of homes rated by the CSCI as 'adequate' or 'good'.

2 Enforcement action is the legal action taken by CSCI when a care home persistently fails to comply with the law or provides unsafe care. It can range from immediate requirements being issued to cancellation of registration in extreme cases.

Inspectors observed between three and five people in each of the 100 care homes. In total, inspectors observed 424 people. People were chosen for observation because they had a diagnosis of moderate to advanced dementia. Around 200 hours of observation were gathered, equating to about 840 hours of people's experience. Inspectors aimed to choose people they observed to represent a broad range of people living in the home (see Table 2 at the end of this introduction).

In addition to the data from the thematic inspections, we held workshops with 20 people with dementia and carers and 24 representatives from care providers and their organisations, voluntary organisations, academics and researchers, local councils, Skills for Care, the Healthcare Commission and the Social Care Institute for Excellence (SCIE). We also drew upon research and literature in this area.

This report

This report is divided into two parts. Part one provides the findings from our inspections and begins with a review of current policy and practice developments – chapter 1. The findings are organised to each address one of the above study questions – chapters 2 to 4. Positive practice is highlighted throughout the report and given special attention in chapter 5. The final chapter presents conclusions about the way that care is delivered and its impact on the well-being of people.

Part two describes our use of SOFI as part of CSCI's approach to regulation. We present three example analyses of SOFI scores – how people spend their time, levels of well-being, and communication. It is important to note that these examples of analysis are derived *only* from SOFI observations and not inspectors' judgements of services overall, which are based on a number of sources of evidence.

Our report is timely given increasing concerns and evidence about the quality and adequacy of care and support for people with dementia and the development of a new national strategy for people with dementia and their carers. This is about people's basic human rights, and the principles of fairness, respect, equality and dignity as set out in the Human Rights Act 1998.[3]

3 *Human Rights Act 1998* – Chapter 42. London: Stationery Office.

Table 1: Characteristics of the 100 inspected care homes

Care home characteristics	Number of care homes
Location:	
Urban	61
Rural	20
Urban/rural mix	19
Care home type:	
Residential care	61
Nursing care	39
Registration category:	
Homes that specialise in the care of people with dementia	59
Older people homes[4]	41
Registered places:	
12–20	10
21–30	21
31–40	28
41–50	11
51–60	15
61–70	3
71–80	3
81–90	6
91–100	2
150	1
Ownership:	
Private	80
Voluntary and charitable trusts	10
Local councils	10
Quality rating:	
New	1
Poor	5
Adequate	40
Good	42
Excellent	12

4 Homes for older people were included when a large proportion of people living in the home had dementia.

Table 2: Characteristics of the 424 people observed[5]

Characteristics of people observed	Number of people[5]
Gender:	
Women	312
Men	98
Age range:	
Under 65	15
66–75	49
76–85	175
Over 85	134
Ethnicity:	
White British	333
White other	5
Asian/Asian British	8
Black/Black British	10
Chinese	1
Other	32

5 Numbers do not add to 424 as inspectors' fieldnotes did not always record the characteristics of people observed.

Part One

The quality of care for people living with dementia in care homes

Chapter 1

Policy and practice context

Key points:

- There are growing numbers of people living with dementia in care homes, currently estimated at 244,000 people.
- Government policy promotes personalised care to enhance personal dignity and respect which is about understanding fully people's lives, hopes and expectations.
- Excellent care based on good evidence of what works does exist but Government has acknowledged the evidence of a series of reports that best practice is not yet universal and is developing a national strategy to improve support to people with dementia and their carers.
- One of the themes of the new national strategy is improving the quality of care for people with dementia. This report focuses on the quality of care provided in care homes.

1.1 People with dementia and national service trends

There are over 560,000 people in the UK living with dementia. This has an economic impact on the economy of around £14 billion per year.[6] People with dementia should have the choice to be supported to live in their own homes for as long as they wish.

6 House of Commons Committee of Public Accounts (2008). *Improving services and support for people with dementia.* Sixth Report of Session 2007–08. London: Stationery Office.

However, people are not always able to have sufficient or appropriate services to support them at home when they are in the moderate to late stages of dementia.

When caring at home breaks down, people with dementia may be admitted to hospital. They are more likely to experience delays in discharge from hospital and in many cases are discharged from hospital straight into a care home.[7, 8] A recent National Audit Office (NAO) study found:

- people with dementia are estimated to make up half of people who remain in hospital unnecessarily
- only 58% of community mental health teams work closely with acute trusts to manage discharge
- in one area, 68% of people with dementia in acute beds did not need to be there and the average length of stay for people with dementia was 44% longer than for older people without dementia.[9]

It is estimated that two thirds of people living in all care homes (244,000 people) have some form of dementia and about 28% of care home places are registered to provide specialist dementia care.[10] Increasing numbers of people living in care homes are projected – one estimate predicts a 63% rise in care home places between 1998 and 2031, based on present service usage.[11]

7 Commission for Social Care Inspection (2004). *Leaving hospital – the price of delays*. London: Commission for Social Care Inspection.

8 Commission for Social Care Inspection (2005). *Leaving hospital – revisited: a follow-up study of a group of older people who were discharged from hospitals in March 2004.* London: Commission for Social Care Inspection.

9 National Audit Office (2007). *Improving services and support for people with dementia.* London: Stationery Office.

10 Care homes registered to provide specialist dementia care are different from care homes for Ider people because they provide care primarily for people with dementia whose care needs are of a degree that they cannot be met by general services. Care homes need to register to provide specialist dementia care when:

- their primary focus is dementia and they have designed the service specifically for people with dementia who need specialist care that cannot be met by general services
- they have adapted or need to adapt major elements of their general social care or nursing care to meet the significant dementia-related needs of a majority of their clients.

Care homes registered to provide dementia specialist care need to show that their staff have the right skills and that the right environment is in place to meet the needs of people with dementia.

11 Alzheimer's Society (2007). *Dementia UK. A report to the Alzheimer's Society on the prevalence and economic cost of dementia in the UK produced by King's College London and the London School of Economics.* London: Alzheimer's Society.

1.2 Quality of care and quality of life

People with dementia moving into care homes face enormous challenges. In addition to declining cognitive powers such as remembering, reasoning and being aware, and arguably an increased need for familiarity and human contact, people have to cope with a new and often unpredictable care environment. They also may be cared for by people who often know very little about them and who, in some instances, focus on their safety rather than their emotional well-being.

People with dementia living in care homes are at risk of developing behavioural and psychological symptoms of dementia such as agitation and disturbed moods. People with dementia are also at risk of becoming delirious or confused if physical health problems are not addressed promptly.[12, 13, 14] Depression is often undiagnosed.[15, 16]

We know from our inspections that people with dementia do not always receive good person-centred care – where care focuses on the person using services and is delivered in ways that promote independence, autonomy and choice. Studies have also indicated that some people with dementia living in care homes may have a poor quality of life.[17, 18] The Alzheimer's Society undertook a survey of 4,084 carers, care home workers and managers.[19] The survey found that people with dementia were not always afforded dignity and respect. 'Dementia' became a label behind which other care needs were often lost. Lack of activity and stimulation was highlighted as a particular problem with 54% of carers reporting that their relative did not have enough to do. A number of carers reported that people living in the home were left

12 Brodaty H, Draper B, Saab D, Low L F, Richards V, Paton H and Lie D (2001). Psychosis, depression and behavioural disturbances in Sydney nursing home residents: prevalence and predictors. *International Journal of Geriatric Psychiatry,* 16(5): 504-512.

13 Margallo-Lana M, Swann A, O'Brien J, Fairbairn A, Reichelt K, Potkins D, Mynt P and Ballard C (2001). Prevalence and pharmacological management of behavioural and psychological symptoms amongst dementia sufferers living in care environments. *International Journal of Geriatric Psychiatry,* 16(1): 39-44.

14 Pitkala K H, Laurila J V, Strandberg T E and Tilvis R S (2004). Behavioral symptoms and the administration of psychotropic drugs to aged patients with dementia in nursing homes and in acute geriatric wards. *International Psychogeriatrics*, 16(1): 61-74.

15 Menon A S, Gruber-Baldini A L, Hebel J R, Kaup B, Loreck D, Zimmerman, S I, Burton L, German P and Magaziner J (2001). Relationship between aggressive behaviors and depression among nursing home residents with dementia. *International Journal of Geriatric Psychiatry*, 16(2): 139-146.

16 Evers M M, Samuela S C, Lantz M, Khan K, Brickman A M and Marin D B (2002). The prevalence, diagnosis and treatment of depression in dementia patients in chronic care facilities in the last six months of life. *International Journal of Geriatric Psychiatry*, 17(5): 464-472.

17 Hoe J, Hancock G, Livingston G and Orrell M (2006). Quality of life of people with dementia in residential care homes. *British Journal of Psychiatry*, 188(5): 460-464.

18 Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum (2007). *My home life. Quality of life in care homes. A review of the literature*. London: Help the Aged.

19 Alzheimer's Society (2007). *Home from home. A report highlighting opportunities for improving standards of dementia care in care homes*. London: Alzheimer's Society.

alone in their room for hours with no attempt from staff to engage with them. These problems were particularly acute for people with severe dementia.

1.3 Guiding principles

Putting People First[20] (a joint protocol between central and local government, the care sector's professional leadership, providers and CSCI) emphasises that the care system should ensure people have the best possible quality of life, irrespective of illness or disability, and retain maximum dignity and respect.

A SCIE practice guide, Dignity in care, based on consultations with older people, their carers and care workers, identified four overlapping themes with regards to dignity:

- Respect, shown to you as a human being and as an individual, by others, and demonstrated with courtesy, good communication and taking time.
- Privacy, in terms of personal space; modesty and privacy in personal care; and confidentiality of treatment and personal information.
- Self-esteem, self-worth, identity and a sense of oneself, promoted by all the elements of dignity, but also by 'all the little things' – a clean and respectable appearance, pleasant environments – and by choice, and being listened to.
- Autonomy, including freedom to act and freedom to decide, based on opportunities to participate, and clear, comprehensive information.[21]

The National Institute for Health and Clinical Excellence (NICE) and SCIE guidelines on supporting people with dementia and their carers outline best practice based on the principles of person-centred care which recognise the:

- human value of people with dementia, regardless of age and cognitive ability, and those who care for them
- individuality of people with dementia, with their unique personality and life experiences among the influences on their response to, and experiences of, their illness
- importance of the perspective of the person with dementia
- importance of relationships, interactions and engagement with others and the potential for promoting well-being.[22]

20 Her Majesty's Government Ministerial Concordat (2007). *Putting People First. A shared vision and commitment to the transformation of adult social care.* London: Department of Health.
21 Social Care Institute for Excellence (2008). *Dignity in care*. London: Social Care Institute for Excellence.
22 National Institute for Health and Clinical Excellence and Social Care Institute for Excellence (2006). *Dementia. Supporting people with dementia and their carers in health and social care*. London: National Institute for Health and Clinical Excellence.

1.4 Improving practice

Most evidence points to the need for an approach to improve the quality of care that focuses on the individual and where a well-trained care team work toward helping people live life to the full.[23, 24, 25, 26, 27, 28, 29] For example, the Enriched Opportunities Programme[30] offered a multi-level approach to improving the quality of care which included a strong emphasis on dementia care leadership and expertise, a trained care team with empathy for people's experience and a programme of care and activity geared to meet the needs of all individuals. As a result, it demonstrated that the quality of outcomes was improved for people living in three care homes that specialise in the care of people with dementia.

People's gender, socio-economic status, ethnicity, culture and sexual orientation also shape their experiences of care.[31, 32] Tailoring care to people's needs must also involve understanding their cultures and developing the knowledge and skills of care staff accordingly.

The House of Commons Committee of Public Accounts[33] drew attention to the lack of staff with appropriate training to care for people with dementia in care homes. Few care staff have specialist nursing qualifications or training in dementia care. High staff turnover and high vacancy levels compound staffing problems. There is also evidence that people working in the care home sector feel demoralised and

23 Marshall M J and Hutchinson S A (2001). A critique of research on the use of activities with persons with Alzheimer's disease: a systematic literature review. *Journal of Advanced Nursing*, 35(1): 488-496.
24 Camp C J and Skrajner M J (2004). Resident-Assisted Montessori Programming (RAMP): training persons with dementia to serve as group activity leaders. *Gerontologist*, 44(1): 426-431.
25 Gitlin L N, Liebman J M S and Winter L (2003). Are environmental interventions effective in the management of Alzheimer's disease and related disorders? A synthesis of the evidence. *Alzheimer's Care Quarterly*, 4(2): 85-107.
26 Brenner T and Brenner K (2004). Embracing Montessori methods in dementia care. *Journal of Dementia Care*, 12(3): 24-26
27 Cohen-Mansfield J (2005). Nonpharmacological interventions for persons with dementia. *Alzheimer's Care Quarterly*, 6(2): 129-145.
28 Orrell M, Spector A, Thorgrimsen L and Woods B (2005). A pilot study examining the effectiveness of Maintenance Cognitive Stimulation Therapy (MCST) for people with dementia. *International Journal of Geriatric Psychiatry*, 20(5): 446-451.
29 Featherstone K, James I A, Powell I, Milne D and Maddison C (2004). A controlled evaluation of a training course for staff who work with people with dementia. *Dementia*, 3(2): 181-194.
30 Brooker D, Woolley R and Lee D (2007). Enriching opportunities for people living with dementia in nursing homes: an evaluation of a multi-level activity-based model of care. *Aging and Mental Health*, 11(4): 361-370.
31 Marshall M J and Hutchinson S A (2001). A critique of research on the use of activities with persons with Alzheimer's disease: a systematic literature review. *Journal of Advanced Nursing*, 35(1): 488-496.
32 Commission for Social Care Inspection (2008). *Putting People First: equality and diversity matters. Providing appropriate services for lesbian, gay and bisexual and transgender people*. London: Commission for Social Care Inspection.
33 House of Commons Committee of Public Accounts (2008). *Improving services and support for people with dementia.* Sixth Report of Session 2007–08. London: Stationery Office.

are undervalued by the public.[34] In addition, a staff team that does not reflect the culture, especially the language mix, of people living in the home can also be problematic. When a person finds verbal communication increasingly difficult as a result of dementia it is important that care staff are able to understand and respond in people's chosen, or first, language.

There are now a number of programmes to support positive practice. For example, *My home life*[35] is a collaborative programme bringing together care home providers, commissioners, and older people. The programme aims to improve the quality of life for people living and working in care homes and to share best practice. Whilst not aimed solely at people with dementia, many of the activities and resources include people with dementia.

1.5 The new dementia strategy

Two recent reports highlighted inadequacies in all services for people with dementia – the NAO study *Improving services and support for people with dementia* [36] and the report from the *UK Inquiry into Mental Health and Well-Being in Later Life*.[37]

The Government is now developing a National Dementia Strategy with three key themes:

- improved awareness and understanding of dementia
- early diagnosis and intervention
- improving the quality of care for people with dementia.

This report is concerned with the last theme, and focuses on care provided in care homes.

34 Skills for Care (2007). *National survey of care workers*. Final Report. London: Skills for Care.
35 Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum (2007). *My home life. Quality of life in care homes.* London: Help the Aged.
36 National Audit Office (2007). *Improving services and support for people with dementia*. London: Stationery Office.
37 Age Concern (2007). *Improving services and support for older people with mental health problems. The second report from the UK Inquiry into Mental Health and Well-Being in Later Life.* London: Age Concern.

Chapter 2

Are my wishes respected and my views taken into account?

Key points:

- Good care plans are clearly written, accessible and draw on life histories and are not just a paper exercise. They should be drawn up with the person living in the home and their carers, and all staff should ensure people's choices are put into practice.
- Care plans were much more detailed and fully completed in 26 of the 100 care homes inspected.
- In 25 care homes people living in the home and their carers had been an integral part of the care planning process.
- Poorly written plans that are not holistic, and do not focus on people's abilities, risk being translated into equally poor practice, as inspectors observed.
- Over a third of homes inspected did not meet statutory requirements in terms of the quality of their care planning.

2.1 Introduction

It is not a straightforward matter to discover the wishes and views of a person with moderate to advanced dementia. As dementia progresses it increasingly affects people's memory and their ability to communicate. Staff may care for someone on whom they have little background information on which to judge their wishes and

preferences. However, people with dementia retain the right to make decisions about their own lives. The Mental Capacity Act 2005 empowers people to make decisions for themselves wherever possible, and protects people who lack capacity by providing a flexible framework that places individuals at the heart of the decision-making process.[38]

Well-researched and thought-through care plans, used by all the team, can be an important aid to respecting people's views and ensuring individualised care. Good care planning includes:

- the full involvement of people with dementia and carers
- looking at the whole person and addressing their health, personal care, social and emotional needs and preferences
- drawing up a life history and using it as part of the care plan
- focusing on abilities rather than disabilities
- detailing individualised information that identifies particular needs and shows how staff can effectively address them
- recognition of a person's capacity and how their best interests are going to be promoted
- team work and emphasis on everyone's responsibility to put plans into practice.

2.2 Care planning

The quality of care plans varied among the 100 homes inspected. Within individual care homes the depth and amount of information on people was equally variable. Overall, care plans were much more detailed and fully completed in 26 care homes.

Thirty-nine statutory requirements[39] were made to 31 care homes about the quality of their care planning. Less serious recommendations[40] were also given to 28 care homes to improve various parts of their care planning. The thematic inspection reflects the national figure that only 57% of all care homes for older people meet or exceed the national minimum standards for care planning.[41]

38 Department for Constitutional Affairs (2007). Mental Capacity Act 2005: code of practice. London: Stationery Office.
39 Statutory requirements are actions the care services must take by law in order to comply with the regulations within a reasonable time.
40 Recommendations for improvements based on the national minimum standards. These are not required by law but are things we consider as good practice for the service provider to consider carrying out.
41 Commission for Social Care Inspection (2008). The state of social care in England 2006-07. London: Commission for Social Care Inspection.

2.3 Involving people in planning

In 25 care homes, inspectors indicated that people living in the home and their carers had played an important part in the care planning process.

> *'Each person has a person-centred care plan that reflects their individual needs and wishes. This has been developed with the resident and their relatives. The care plan and an effective key-working system enable the residents to receive the support they need in line with personal preferences and aspirations.'*
> (inspection report)

Innovative approaches were evident; for example, making plans fully accessible:

> *'Plans are in large print with use of colour pictures as aids to communication.'*
> (inspection report)

The best care plans are clearly and sensitively written with detailed information on people's personal preferences.

> *'I wear a light night dress, I like a cup of tea before bed and when in bed please close the door. I would prefer to be washed and dressed by a female carer.'*
> (inspection report describing a good care plan)

Drawing up life histories can help to involve everyone in care planning processes, including carers.

> *'A life history of the person had been drawn up by their family, and staff found these very helpful in getting to know the person and what is important to them. This information was also used to help staff plan appropriate activities.'*
> (inspection report)

When care plans are well constructed, people's individual needs and preferences about their care are more likely to be met.

2.4 Team work

Some homes clearly demonstrated that care planning was an important part of care and staff were provided with specific training to ensure they were able to complete care plans consistently and well. However, in other homes staff were detached from the care planning process.

> *'None of the staff were aware of person-centred care planning; neither had they received training in dementia. The staff said, 'We have nothing to do with the writing up of the care plans, or any changes made at review, the manager sees to all of this'.'*
> (inspection report)

When staff are not fully involved in care planning, the quality of care people received was poor.

> *'Care staff demonstrated a lack of awareness in some areas of care and well-being, and said that they had not read the care plans for these people. For example, one care plan said it was important that a person was able to rest their legs on a footstool to maintain their health and mobility, however during the observation it was an hour before this was offered, and after dinner it was not provided. The person reacted positively when the footstool was offered.'*
> (inspection report)

2.5 Looking at the whole person

Person-centred care plans included information on all areas of people's lives.

> *'A photograph of the person, their family history, information on how their life could be improved, last wishes and religion were noted plus details of interests and hobbies, family contacts and food and dietary needs. Personal care needs arising from culture and diversity were clearly noted and there was evidence of regular reviewing of information.'*
> (inspection report)

Comprehensive care plans were clearly beneficial in helping staff to build relationships with people and understanding their lives.

> *'Staff have managed to adapt care plan paperwork, which tends to be based on physical needs, so that it is more person-centred. For instance, they have taken into account one person's previous occupation when trying to understand why they behave in a certain way. They explained that they consider this information important when supporting the person in their daily life. They also record discussions that they have had with people about their past life...'*
> (inspection report)

In contrast, inspectors reviewed care plans that were not person-centred and contained information that inspectors judged insufficient. Some care plans were particularly task oriented and did not detail people's wishes, desires and choices. The risk is that poor quality care plans translate into poor practice.

> *'We found the care plans to be about tasks rather than about providing care which centres on the person with dementia, their past life, personality, strengths and wishes. This followed through in practice and the care delivered to the residents with dementia focused almost exclusively on doing tasks, there were hardly any examples of the staff sitting with residents and talking to them about their lives, wishes and feelings.'*
> (inspection report)

2.6 Focusing on abilities

Focusing on abilities is one positive step towards helping to maintain people's independence.

> *'The focus of care was building on the strengths each person has rather than the things they are not able to do for themselves. For instance, one person is able to feed themselves if given a spoon...'*
> (inspection report)

In contrast, however, some care plans focused predominantly on people's disabilities. This kind of planning approach is unlikely to support people's independence and autonomy.

> *'We found the care plans were task orientated and almost always start with the words 'inability to', rather than focusing on the things people can still do.'*
> (inspection report)

2.7 Putting plans into practice

Inspectors found examples where care plans were not accurate and up to date and did not reflect what they observed in the home.

> *'One care plan stated that this lady had no communication skills, but in another part of the care plan it stated that if she shouts out it may be an indication of need and that staff should respond and make contact with her. Although this lady did shout out several times, staff did not positively respond to her at all and took very little notice except when handing out drinks. Another care plan stated that a resident needed a 'walking stick' at all times, yet this resident was observed freely moving around the environment without the aid, and staff did not identify this.'*
> (inspection report)

In other homes, however, staff were using information in care plans effectively to ensure appropriate, supportive care was being delivered.

> *'Guidance in the care plans had been followed. For example, one person likes to sit centrally in the lounge so they can 'observe everything' and we saw this to be the case. People were heard being called by their preferred name, as confirmed by them and recorded in their care plans.'*
> (inspection report)

2.8 Making choices

The provision of choice is a key component of assessing the extent to which people's wishes are respected and their views taken into account. Inspectors observed how people living in the home exercised choice, particularly around eating, drinking, personal routines and daily life in the care home.

Of 62 inspection reports that commented on choice in care homes, only 36 indicated people were given opportunities for choice in areas such as meals and activities.

Eating and drinking

In some care homes, for example, people had choice over what they eat and drink, including how they would like their food prepared.

> *'After lunch, the cook spoke to people in the lounge, asking what they would like for lunch the following day. If they did not fancy one of the set choices, she offered to make something especially for them.'*
> (inspection report)

However, other homes were less accommodating. People were given little if any choice over their meals and alternatives were not offered when people were not enjoying or eating their meals. People who were assisted with eating were not given choice about what to eat.

> *'There was no choice given as to what they would like their next mouthful to be.'* (inspection report)

People with advanced stages of dementia were given even less choice at mealtimes.

> *'Meal choices are made verbally on the day; people with communication impairment are provided with food which staff feel they would like.'* (inspection report).

Personal routines and life in the home

Some people clearly had choice in their daily lives.

> *'Examples of this are that everyone is encouraged to make themselves a hot drink whenever they wish to do so. One person has got an ironing board in her bedroom so she can do her own ironing. It was observed during the inspection that people living in the home were able to follow their own routine, getting up more slowly if they wished to do so and spending time in their bedrooms if they preferred. Two of the residents said they liked to stay up later and watch TV in the lounge. The inspector observed that the people living in the home were able to talk to the staff and express their wishes about their daily lives.'* (inspection report)

Others had no choice, particularly as to what they did during the day.

> *'The main source of stimulation for people came from the television that was being used to play CDs. People were not asked what music they wanted to listen to or what programmes they wanted to watch when the TV was put on.'* (inspection report)

Inspectors also witnessed examples where people's freedom and choice of movement were restricted by staff.

> *'One staff member prevented some people moving around by placing their hands on their Zimmer [walking] frames and asking several times where people were going, which resulted in some people looking anxious and submissively sitting back down again.'*

The restriction of people's freedom and choice has been addressed in an earlier CSCI paper – *Rights, risks and restraints.*[42, 43] Inspectors observed how some care homes did not allow people choices about their own care.

> ***'A resident said that they did not want the apron – the member of staff said 'I won't do it up' and the apron remained in place.'***
> (inspection report)

In contrast, inspectors also found good examples of the needs of people being understood and care being delivered sensitively.

> ***'Staff clearly understood the needs of the people they were caring for and were able to explain behaviour demonstrated by one person whilst she was eating her meal. They said this resident used to make bread when she was younger...she blesses the bread and then she will eat her sandwiches.'***
> (inspection report)

2.9 Conclusion

It is not a straightforward matter to discover the wishes and views of people with moderate to advanced dementia. Providing care to people with dementia, often in the later stages of their lives, can be a difficult and demanding job. Comprehensive care planning lays the foundation for good quality care. Good care plans gather together all the available information about the individual and their preferences for care. Without these care plans, staff may find they have little background information on which to judge what someone's wishes and preferences might be. The risk is that poorly written plans, such as those that focus on people's disabilities rather than abilities, are translated into equally poor care practices.

42 Commission for Social Care Inspection (2007). *Rights, risks and restraints: an exploration into the use of restraint in the care of older people*. London: Commission for Social Care Inspection.
43 Commission for Social Care Inspection (2007). *Guidance for inspectors: how to move towards restraint-free care.* London: Commission for Social Care Inspection.

Chapter 3

How am I treated and how do staff communicate with me?

Key points:

- The observation data from 424 people found 94 (22%) of them spent time in a withdrawn mood state during a time of day when people were generally engaged with activities. People who were least engaged were those with a higher level of communication impairment or other impairments. A clustering of these withdrawn behaviours in 15 homes is suggestive of other environmental factors, such as lack of appropriate stimulation.
- We found excellent examples of one-to-one attention and care offered with warmth, understanding and tolerance. But 21 requirements were given to 18 out of the 100 care homes with regard to maintaining people's privacy and dignity.
- Impersonal assistance and a task-oriented approach undermine people's sense of dignity and can lead to people being passive and silent. Some care homes failed to assist people, especially those with the greatest needs.
- The quality of communication, verbal and non-verbal, has a great bearing on how people with dementia feel. There is a strong relationship between positive communications that are friendly and warm and people with dementia feeling happy and relaxed. It is not just negative and disrespectful interactions that leave people with dementia feeling distressed and withdrawn but also 'neutral' styles of communication.

3

3.1 Introduction

> *'Once you've met one person with dementia... you've met one person with dementia.'*[44]

There is a tendency for people with dementia to be regarded by society as 'non-persons' without the rights and attributes that full citizenship implies. Moving into a care home can accentuate the feeling that a person's life is over.

Although dementia is a difficult experience for people, we know that people can still enjoy their life on a day-to-day basis. We do not have a cure for dementia but we do know that supportive skilled care enables people with dementia to experience well-being. Living in a care home does not affect a person's rights as a citizen. Personalised care depends upon people with dementia living in care homes being seen as individuals, each with their own story and unique personality and experiences. It is the person that must be seen rather than the label of a disease.

Most people living with dementia want to continue to do as much for themselves for as long as they can. It is a delicate balancing act for staff to ensure people have the right amount of help so that they do not feel disempowered because too much help has been given, or alternatively feel overwhelmed because insufficient support has been provided. It is often easy to forget these important considerations when the issues are subsumed in a phrase on a care plan that says: *'needs help with activities of daily living and self-care'*.

In this chapter we look at the findings from the thematic inspections about how people are treated and how staff communicate with people with dementia living in care homes.

3.2 How people spend their time

As part of the thematic inspection, inspectors observed 424 people with dementia using SOFI. (Further details of the SOFI are given in chapter 7.) To our knowledge, this is the first time such an in-depth observation has been undertaken across so many care homes. Inspectors' observations found wide variety in how people spent their time:

- 217 of the 424 people observed spent over 75% of the two-hour observation engaged with the world around them.

44 Quotation attributed to the late Tom Kitwood.

- 57 people spent less than 30 minutes of their time engaged with the world around them.
- 10% of care homes had some people who spent 25% or less of their time engaging with anything or anyone.
- People who spent the least time engaged were those with a higher level of communication impairment or other impairments.

Withdrawn behaviour

Inspectors attributed withdrawn behaviour to people being disengaged for a large proportion of their time. In some circumstances this may have been related to long-standing mental health problems such as depression. However, withdrawn behaviour did appear to cluster in some homes. In 15 care homes, 50 to 100% of people experienced some proportion of their time in a withdrawn mood state. This suggests that additional environmental factors, such as a poor culture of care, may have been at work here.

Sleeping

In 17 homes at least 40% of people observed spent more than a quarter of their daytime observation period asleep. Inspectors used their observations as a prompt for questioning and further investigations. Sometimes inspectors found a number of problems associated with people who were sleeping:

- people who slept a lot were on high levels of medication
- staff had difficulty meeting people's needs and often let them sleep
- people became agitated if woken and were subsequently left alone
- there was a lack of stimulation and it was thought people fell asleep because there was nothing to do.

In other situations, however, large amounts of sleep appeared justified to inspectors given people's level of physical frailty. Sleep can be a physical and emotional comfort.

> *'One resident was asleep throughout the observation but is very frail. The staff took time to make sure she was comfortable and warm and adjusted her support cushions regularly. She sighed contentedly several times through the observation and her husband sat with her stroking her hand.'*
> (inspection report)

3.3 The relationship between people's engagement and their mood

We found that when there is an opportunity to be engaged and involved then the vast majority of people with dementia in care homes enjoyed this opportunity.

> *'During the SOFI observation people were heard to say that they were 'tired'; however, when staff approached or if they were spoken to they would become alert and responsive.'*
> (inspection report)

The data from SOFI shows a significant relationship between people being in a happy and relaxed mood state and being involved and engaged in the world around them. People who are involved in more activities and communicate with others experience a greater proportion of time in a positive frame of mind. This finding underlines the importance of opportunities for meaningful activity in care homes.

Example analyses of SOFI data on how people spend their time and levels of observed well-being are detailed in part two of this report.

3.4 Providing assistance

The need for assistance varied from people needing minimal support through to those needing full assistance. Inspectors noted that 35 care homes were doing well in assisting people, where staff listened to, and acted upon, people's requests and actively supported people.

> *'Staff took time to listen to residents, act on any requests and treat people with dignity ... People were made to feel comfortable...'*
> (inspection report)

However, some care homes failed to support people well and did not put actions agreed in care plans into practice.

> *'One individual whose care assessment said that they preferred to use their hands to eat and liked finger foods was fed soft food at lunch time... Another individual appeared to have difficulty in eating the meat in the curry they had for lunch, and spent most of the time just looking at the meal. They received no support from any staff until they had had their meal for over half an hour, by which time it must have been cold. The individual, when asked, said they had finished; they eventually received a rice pudding, which they ate quickly and with ease. When the inspector looked at the individual's care plan it stated that the individual needed a soft diet and/or food cut up and support.'*
> (inspection report)

Inspectors found some staff gave insufficient attention to or had a lack of awareness of the needs of everyone living in the home, especially people with the greatest needs.

> *'Staff ignored or 'missed' out on signals and requests from individuals where they may not have vocalised their needs.'*
> (inspection report)

Inspectors also found some care homes failing to provide individualised care and attention. For example, some staff members assisted more than one person during mealtimes, and some people were helped to eat by a number of different staff members.

> *'People who needed help with their meals had a series of different members of staff stop and help them with one or two mouthfuls before moving on to either continue to give out meals or help someone else. There were no chairs for staff to sit on and this resulted in members of staff bending over people to help them eat.'*
> (inspection report)

> *'One person had a series of different members of staff stop by to give her a forkful of food from time to time without sitting down with her; in 45 minutes she had eaten very little.'*
> (inspection report)

In contrast, inspectors also found examples of skilled and considerate care.

> *'One person was assisted to eat in a very caring and unhurried way. The staff member told the resident what was on each fork before she offered it to her. She also asked for regular feedback about whether she was enjoying it, whether she wanted more and if she would like a drink.'*
> (inspection report)

And there were examples of help which was warm, understanding and sensitive.

> *'Comments such as 'is that nice' and 'are you enjoying that' were overheard. The resident looked calm and relaxed and appeared to enjoy their meal and the one-to-one attention being provided.'*
> (inspection report)

> *'The staff member assisted her very discreetly at first. When it became clear that the lady was able to take over, and feed herself, the staff member stayed beside her, chatting, and gently prompting her.'*
> (inspection report)

Inspectors noted that staff in some care homes were discreet in their discussions of personal and private issues with people.

> *'Staff were observed ensuring toilet doors were closed, using the preferred terms of address when talking to residents and offering assistance in a discreet and respectful manner.'*
> (inspection report)

But inspectors gave 21 requirements to 18 care homes with regard to maintaining people's privacy and dignity. This means that one in five of the homes we inspected did not meet the requirements of the law in terms of affording people dignity and respect.

> *'On occasions, we saw some staff talking over people to other members of staff, as they assisted them to the toilet, and one staff member said indiscreetly that they needed to change a person's 'pad'.'*
> (inspection report)

3.5 Communication

Anxiety, anger and shame are the emotional undercurrents to dementia. Negative or uncaring communication can intensify these feelings; positive communication provides a sense of safety and acceptance. Inspectors used SOFI to examine the amount of communication between staff and people being observed.[45]

Positive communications

Using SOFI data (as detailed in part two) we found a strong statistically significant relationship between positive staff communications and positive state of well-being for people living in the homes.

When staff interact in a positive way with people, they spend a greater proportion of time in a positive mood. Communicating positively with people with dementia is not just good manners. It actually has a significant effect on how people feel.

> *'One carer was observed throughout the entire inspection to interact positively with residents, providing warmth, acknowledgement and respect of individuals' needs. Several residents were observed to respond to this carer by either smiling, providing good eye contact or by making positive verbal comments. When questioned by the inspector the carer was clearly knowledgeable of individual residents' care needs, personal preferences, likes and dislikes. One resident was overheard to say as the carer left the lounge area 'she's lovely' and 'I like her'.'*
> (inspection report)

Using physical touch is an important part of communicating and interacting with people with dementia.

> *'People clearly enjoyed the company of staff and there were excellent examples of staff showing warmth and genuineness, such as hugging and holding hands.'*
> (inspection report)

Speaking and communicating with people in ways that demonstrate sensitivity to their emotional needs had a clearly positive impact on them. Non-verbal communication is especially important when people are anxious or distressed.

45 SOFI refers to different styles of interaction with people living in the home:

- Positive: including warm, supportive, friendly and caring approaches.
- Neutral: task-orientated questions such as 'do you want a drink?'.
- Negative: for example, cold or disrespectful comments that undermine people's well-being and treating people like children.

More detailed information about SOFI is given in chapter 7.

> *'Some staff in particular were very warm and accepting to all people who used the service. These staff members frequently held or touched people who were distressed and this seemed to provide comfort to them.'*
> (inspection report)

Communicating in a disrespectful and 'negative' way

There was a strong correlation between high levels of negative communications and low levels of positive mood. This underlines the importance of how staff interact with people. It is not just an issue of being disrespectful when negative communications occur; it has a direct observable effect on people's well-being. This effect is likely to be worsened if experiencing disrespectful, negative communication is an everyday occurrence.

Inspectors observed a number of instances when staff were insensitive to people's emotional needs and feelings.

> *'One resident who was eating off her knife had it removed altogether and was told that she was 'playing with it'. Another resident said she wanted her Mum and the staff member replied, 'she doesn't want you'.'*
> (inspection report)

There were a number of cases when people were treated like children.

> *'There were many examples of staff treating residents with dementia like children, eg they referred to aprons used to keep people clean during lunch openly as 'bibs'.'*
> (inspection report)

Staff found it difficult to feel a personal connection to some people.

> *'One member of staff was observed ignoring a resident who was trying to gain their attention and searchingly kept looking into their face. The member of staff was observed to interact with other staff members rather than with individual residents and as a result of this the resident gave up and became withdrawn and entered into their own inner world.'*
> (inspection report)

Communicating in 'task-oriented' ways

Our analyses of SOFI data also demonstrate a strong statistically significant correlation between high levels of neutral communication and low levels of positive mood. Neutral communications focus on something that needs to be done and

typically lack empathy and warmth. An example of neutral communications would be asking someone swiftly if they need the toilet.

Neutral communications appear to have a negative effect on the mood of people with dementia living in care homes. A family carer, commenting on his experiences when visiting his wife in a care home, said:

> *'The residents are being deprived of the 'social/emotional' language that is so much a part of the human condition. I have sat with residents to share teatime and always found a mixture of memories etc and encouragement to eat come well together. The tone and volume is important too of course – gently poetic rather than authoritatively peremptory!'*
> (email from family carer)

3.6 An inspector's example of improvements in practice following an inspection using SOFI

An inspector undertook a SOFI observation in a key inspection[46] of one large home with over 100 beds, where over half of the people living in the home have dementia. Very poor outcomes were observed for people living in the home.

> *'People living in the home were seen to be treated as objects without needs, wishes or emotions. They were not treated with respect and dignity nor was any attempt made to understand their individuality. We were not able to identify where the residents got their comfort or identity from. The walls were bare, there were no stimulating objects such as books, magazines or any tactile objects.*
>
> *Staff did not speak to the people living in the home or help people speak to each other, the result of this was a silent room full of silent residents who drifted in and out of sleep.'*

Inspectors fed back the detailed findings from the SOFI observation, noting how staff worked in very task-oriented ways. Staff did not appear to work in ways that understood people or could effectively meet people's needs. Reviews of records and interviews with staff identified a lack of staff training.

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46 Key inspections are a thorough look at how well the service is doing and are usually unannounced. They take into account detailed information sent to us by the service's owner or manager, the views and experiences of people using the service and any other relevant information we have received since the last inspection. Our inspectors will look at how well the service is meeting the standards set by the Government. This information is then used to calculate a quality rating. The rating may be assessed as 'poor' (zero star service), 'adequate' (1 star service), 'good' (2 star service) or 'excellent' (3 star service).

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The manager of the home used the detailed feedback constructively to identify a number of key changes to care ethos and practice within the home.

Six months later, a random inspection was scheduled and inspectors witnessed a much improved and happier home. People within the home were valued for what they can achieve, and they are provided with comfort, identity and acceptance.

> *'On this inspection the environment had changed completely. The unit was a happy busy place where people were treated as individuals. Staff knew the needs and wishes of the people who live there. All the people observed had access to objects that appeared to offer them comfort and the atmosphere was homely. All the people observed were occupied in some manner. Staff were observed holding the hands of people and laughter was frequently heard throughout the observation.*
>
> *Staff were observed to be proactive in ensuring people were not left alone and isolated. In the home people with dementia are cared for and we observed staff ensuring all people were attended to in a gentle, caring manner. Staff were aware of everyone and nobody was excluded. They paid particular attention to those who were unable to communicate. All staff observed showed good communication skills.*
>
> *For example one woman was upset and worried about her son visiting. A member of staff spent time with her reassuring her that her son was going to visit, and when she could not be fully reassured, the staff member went and got a letter her son had written for such occasions and read it to her. This made her smile and she was visibly relaxed.'*

3.7 Conclusion

The quality of staff communications has a great bearing on how people with dementia feel. There is a strong relationship between positive communications that are friendly and warm and people with dementia feeling happy and relaxed. It is not just negative communications that are associated with people with dementia feeling distressed and withdrawn but also 'neutral' styles of communication. This underlines the importance of all staff who are in contact with people with dementia having good communication skills and a warm, proactive, supportive and understanding approach. There is a responsibility for care providers to have processes in place to ensure that this is always the case.

Chapter 4

Do I have opportunities to relate to other people that are important to me?

Key points:

- Some care homes took positive steps to ensure people maintain important relationships but this was not happening in every care home.
- A large number of people living in care homes did not communicate with others also living there. 177 people (42%) spent no time at all in contact with other people living in the home during the observations.
- Higher levels of interactions with others living in the home did seem to relate to well-being. For example, 33 out of the 50 people who had contact with others spent over half of their time in a positive mood.

4.1 Introduction

Family carers often struggle with their own feelings when the person they care for moves into a home. It is a major life event for the person with dementia as well as their carers. Carers may experience stress, anxiety and feelings of loss but many want to continue to have an active role in the life of the person living in the home.[47], [48] Where care homes do not understand and accept these feelings, and carers are not made to feel welcome, they may be increasingly reluctant to visit. This can deny people with dementia an important link with the past and their core identity.

47 Hellström I, Nolan M and Lundh U (2007). Sustaining 'couplehood': spouses strategies for living positively with dementia. *Dementia*, 6(3): 383-409.
48 Davies S and Nolan D M (2006). 'Making it better': self-perceived roles of family caregivers of older people living in care homes. *International Journal of Nursing Studies*, 43(3): 281-291.

Care staff can feel challenged and compromised by family carers and this too can lead to breakdowns in communication.

It is also important for care homes to provide opportunities for people to engage with the wider community, such as enabling people to maintain friendships, attend clubs or faith centres.

4.2 Contact with others living in the home

Inspectors observed little contact and communication between people living in the homes. Even when people were eating together in a communal situation, contact with others was limited. The percentage of all contacts that occurred between people living in the home was limited to just 9%. It often needed staff or visitors to encourage conversation for communication to occur.

Inspectors found that 177 people (42%) spent no time at all in contact or communication with other people living in the home during the observations. Only four people (1%) were communicating with other people living in the home in over half of these kinds of observation.

Higher levels of interactions with others living in the home did seem to relate to well-being. For example, 33 out of the 50 people observed whose contacts were with others living in the home spent half or more of their time in a positive mood. Inspectors found good examples of ways to help people living in the home to interact with each other and care homes giving people freedom to choose their own activities.

> *'During the visit a game of catch with a sponge ball was being enjoyed by a group of people in the lounge. There were also magazines, which several residents were enjoying. People were afforded the freedom to come and go as they please; some people were enjoying the sunshine in the garden; others were exploring different areas of the home or sitting in the entrance hall.'*
> (inspection report)

4.3 Contact with carers and visitors

Unsurprisingly, inspectors observed very little interaction with visitors during lunch. A different picture would have emerged at a different time of day. However, despite this, 88 people (21%) spent some of their time with a visitor.

Good homes were noted to be warm and welcoming to visitors.

> *'A visitor commented that his relative had lived at the care home since it opened. He said that his relative received 'excellent care', and that 'I cannot praise them highly enough'. Staff actively encourage people to maintain contact with their relatives. They laid a place at the dining table so that a visitor could have lunch with his relative, and help her to eat her meal.'*
> (inspection report)

In some homes, the maintenance of relationships with family members was actively supported, and some people living in the home enjoyed visits out to their relatives or invited people to have meals within the home.

> *'The service periodically arranges what it calls 'couples supper', providing a candle-lit meal with gentle music for people and their spouses or partners, so that they have some quality time together.'*
> (inspection report)

All three of the group discussions we held about early findings considered the potential value of using volunteers in care homes. Some care providers noted that they have tried to get people to volunteer in care homes, but have found it difficult to attract people. Group discussions with people with dementia and carers alerted us to some good examples of volunteering practice, including one former carer who acted as a personal companion for people living in a care home.[49, 50]

4.4 Pets and animals

Some care homes recognised people's relationships with their pets and tried to ensure these continued when people moved into the home.

> *'In certain circumstances, new residents are able to bring existing pets with them when they move into the home.'*
> (inspection report)

> *'A resident was clearly upset, but the carers went and brought the home guinea pig which the lady happily sat and petted for over two hours.'*
> (inspection report).

49 Ellis, J (2007). Volunteer in a dementia-registered nursing home. *Working with Older People*, 11(1): 28-31.
50 Ellis, J (2007). Sharing pictures in a nursing home. *Signpost*, 12(2): 33-35.

4.5 Other opportunities

Many people living in care homes do not have relatives and friends who visit regularly and have difficulty using community facilities. It is therefore important to have different activities going on within the home. There were a number of good practice examples cited in reports.

> *'People are supported to live fulfilling lives through the opportunity to take part in activities and freedom to come and go in the home. There are activities co-ordinators in addition to care staff who also engage people in activities.'*
> (inspection report)

People with dementia and carers in one discussion group also emphasised the importance of people leading an active life.

> *'I went to visit a very good home. There was a lovely garden, with some raised flowerbeds. The staff told me that people could plant the beds up and look after these themselves. I thought that was a really good idea.'*
> (people with dementia and their carers group discussion)

4.6 Conclusion

People living with dementia are at risk of losing contact with their friends and family. This chapter has focused on positive practice that helps people living in care homes to maintain links with others as well as relating and communicating with others living in the home. When care homes make an effort to welcome and maintain links with others, people living in the homes demonstrate higher levels of well-being.

Chapter 5

Supporting positive practice

Key points:

- Our analysis suggests:
  - Better performing homes tended to be smaller in size, but not exclusively.
  - Being a home that specialises in the care of people with dementia or having a dedicated unit did not guarantee excellence in the quality of interpersonal care. This needs to be seen in the context that some of these facilities are caring for people with particularly challenging and complex needs.
  - Little difference was found between those homes performing well and those performing poorly in terms of the built environment.
- Leadership is vital to promote and model the right attitudes and to ensure quality of life for people with dementia. 41% of all poorly performing homes had vacancies for managers. None of the well-performing homes had vacant manager posts.
- Staff recruitment and retention and staffing levels can affect the quality of care provided. Inspectors issued 10 requirements to 10 out of 100 homes in relation to staff numbers and skill mix.
- In five homes inspectors rated staff training as 'excellent', and 'good' in a further 16. All the top-performing homes had consistently invested time and resources in dementia awareness and person-centred care training.

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- However, inspectors gave 21 requirements to 21 homes on staff training. There were also 28 recommendations on staff training.
- Our analysis showed a statistically significant relationship between staff training and development and people's well-being.

5.1 Introduction

> *'Good practice enriches the environment for everyone.'*
> (policy makers' group discussion)

This study demonstrates that the quality of staff communication with people with dementia has a major impact on their quality of life (as discussed in chapter 3). Not only is there a strong relationship between negative staff communications and low levels of well-being, but high levels of neutral communications are also strongly related to low levels of well-being in people with dementia.

This confirms the importance of a positive communication style with people with more advanced dementia.

People who are isolated did not communicate with other people living in the home or staff. By and large, as dementia progresses it becomes more difficult for people to initiate social contact even if they spend their days in communal settings. If staff do not communicate well with people living in the home, then it is unlikely that people living there will communicate with each other.

It is important to consider what factors support a home to encourage good and proactive communication with people. We examined the characteristics of homes that were performing well in how they communicated with people and those homes that were performing poorly, to explore the factors. These included the type of home, training and support to staff, and policies and procedures in homes.

We compared 19 homes where inspectors judged that people were receiving high levels of positive communication with 22 homes where inspectors judged that communications were very poor.

In this chapter we draw upon the full inspection reports as well as discussions from a series of stakeholder meetings.

5.2 Types of home

In summary, the analysis of our data on the 'top' and 'lower' performing homes found:

- no evidence that the type of provider (private, voluntary or council-run) is a guarantee of excellent or poor quality communication
- a tendency for the better performing homes to be smaller in size than those performing less well, but not exclusively
- a greater proportion of homes that specialise in dementia care in the 'poor' category, possibly reflecting that these homes are most likely to care for people with more advanced dementia and more challenging behaviour
- specialist 'units' do not always appear in the 'top' performers
- an even spread of homes registered for nursing care in both 'top' and 'poor' groups
- little difference between those homes performing best and those poorly in terms of the built environment – very few of either category were purpose-built.

5.3 Care home ethos, policies and procedures

Inspectors examined the ethos of care, as reflected in care homes' statements of purpose, and policies on privacy and dignity. The majority of homes (79) received some positive feedback on their policies and procedures.

> *'The statement of purpose states that 'Services are delivered by skilled and continually trained staff group who respect individuals' independence, dignity and privacy, cultural and religious needs'. It also explains about empowering and enabling residents, discusses in detail cultural differences and how these are considered, eg use of signage, activities, layout of building and consultation. In addition there is a 'charter of rights' (in large print) which gives examples of how respect, dignity and privacy are put into practice using a person-centred approach to care.'*
> (inspection report).

However, 58 out of 100 care homes received feedback indicating that improvements to policies and procedures should be made.

Clearly a written statement of purpose does not always reflect the care people actually receive.

> *'We found that the statement of purpose was not reflective of the service being provided and the absence of a policy on issues of privacy and dignity leaves staff without clear guidelines to follow.'*
> (inspection report)

5.4 Leadership

Effective leadership is vital, as are senior staff who can provide a role model in good communication and care.

> *'Effective managers who are good communicators themselves will find the right staff, they will know what the right training is and they will advocate for their residents with the owners.'*
> (care home provider, stakeholder workshops)

Of the 22 homes that were not performing well, nine (41%) had vacant manager posts. None of the well-performing homes had vacant manager posts.

Care home providers have highlighted difficulties in recruiting good managers and, in some places, competition between care homes to recruit from the small number of leaders locally.

5.5 Staff recruitment and retention

Care homes face challenges in the recruitment and retention of good quality staff. Care staff are not well paid and many homes said they had lost staff when competing job opportunities arose locally. A high turnover of staff is unhelpful for people with dementia who can take a long time to get to know staff and who need continuity in care. These problems were not just limited to care staff. Care home providers also reported the pool of good registered mental health nurses and registered general nurses was getting smaller.

Some care home representatives reported problems in recruiting applicants with a good grasp of written and spoken English. This can be a particular issue when such a high premium is placed on excellence in communication with people with dementia.

5.6 Staffing levels

Inspectors found inadequate staffing levels explained some poorly organised activities and mealtime arrangements.

> *'From midday, staffing levels decreased from three members of staff to two. This was observed to have a detrimental affect on the delivery of the lunchtime meal to residents and resulted in one resident not having their lunch until 14.15.'*
> (inspection report)

Poorly managed mealtimes can sometimes lead to frustration and to people leaving the dining area because they are confused about why they are there. It is important for mealtimes to be carefully planned and well managed. Some care homes deployed staff effectively to deal with the increased pressures during the busy periods.

> *'Management of meal times was well co-ordinated with those requiring assistance enabled to have lunch first. Catering staff provide assistance at meal times to ensure that there are sufficient numbers to provide support.'*
> (inspection report)

There is some debate as to whether more staff would significantly impact on the quality of care. Inspectors noted particularly low levels of staff on duty in 15 of the 100 care homes. Inspectors gave 10 requirements to 10 homes in relation to the number and skill mix of staff.

> *'On the afternoon there was only one member of care staff on duty for up to 14 residents due to a member of staff not being able to undertake their shift. Residents were seen becoming disorientated with their surroundings, asking the inspector 'Can you find someone to help me back to the lounge?' and another resident was seen using a toilet, exposing themselves with no staff available to maintain their dignity.'*
> (inspection report)

In contrast in other homes inspectors noted

> *'There were 17 residents with four staff members present and the staff were talking to the residents in a way that was both respectful and inclusive. They were getting down to the same level as the people they were caring for and making eye contact and if one of the residents wasn't joining in the conversation, they were drawn into it.'*
> (inspection report)

Many workshop participants thought staffing levels on their own would not ensure quality care. The ethos of the home, the quality of staff and staff with the right skill mix are all important factors in ensuring good personalised care.

5.7 Staff training and development

Inspectors observed that some staff appear to be natural communicators and connect well with people with dementia. Other staff, however, need encouragement to communicate well, which can be achieved through good induction, training, mentoring and supervision.

> *'When new staff start to work at this home, they have a 12-week induction period, and are given a very detailed staff handbook. This contains lots of information about people's rights to privacy and dignity, and to be treated as individuals.'*
> (inspection report)

The 19 'top' well-performing homes had all consistently invested time and resources in dementia awareness and person-centred care training. Our analysis showed a statistically significant relationship between staff training and development and people living in the home experiencing good levels of well-being.

On the other hand, there was evidence of dementia-specific training being undertaken in a small number of poorly performing homes. In these homes other factors such as vacant management posts and lack of take-up of training available seemed to militate against this being put to best effect. Training alone is not sufficient to improve the quality of care.

In five homes inspectors rated staff training as 'excellent' and 'good' in a further 16. Good quality specialist training comprised a full package or programme of training to staff. However, inspectors gave 21 requirements to 21 care homes and 28 recommendations on staff training.

> *'We found that many of the staff working on the unit have not had training in understanding how to deliver person-centred care to the residents with dementia and refuse to do this training. Their lack of awareness showed throughout our observation.'*
> (inspection report)

Inspectors and providers indicated that the quality of training could be variable. In some cases care homes found training did not always appear to be of a quality or format that had any significant impact on practice, staff knowledge or skills.

> *'The care plans and the training provided has not enabled staff to fully understand what person-centred care is, how dementia affects people and how they can help them. This means that people with dementia might not receive the care and support they need. Staff said they had done a distance-learning course about dementia. Their understanding about the different types of dementia, how they affected people and person centred care varied from minimal to basic.'*
> (inspection report)

In contrast, inspectors also found care homes operating with a good range of training provision which was clearly beneficial:

> *'Staff felt they received good training opportunities, and had done specific training in areas such as dementia awareness, and National Vocational Qualifications in care practice, communication skills, abuse and challenging behaviour.'*
> (inspection report)

Discussions with care home providers identified the need for more consistent training around core competencies which was properly accredited and delivered by good quality trainers. Providers commented on:

- People with a particular certificate may not have the same knowledge, understanding or skills due to differences in training quality.
- Insufficient monitoring of standards of National Vocational Qualification assessors. These can be very variable and some will allow very small portfolios whilst others will insist on much greater depth of work to pass.
- The quality of National Vocational Qualifications appears to have reduced over recent years and training is not as effective as it could be in developing the skills of direct care staff.
- Poor quality training agencies that go into receivership mean ongoing training investments for staff are immediately lost.
- The application of training needs to be assessed rather than staff being awarded a certificate for course attendance alone.

People with dementia and their carers also emphasised the importance of providing culturally appropriate dementia care.

It is important for care staff to receive regular programmes of training. Some care homes used training matrices to ensure all staff receive training over a rolling 12-month period.

5.8 Staff training and its relationship to the positive mood of people living with dementia

Where staff had not received training, inspectors observed a lack of knowledge and skills which were demonstrated in routine practice.

> *'We found the care staff have not had training in understanding how to deliver person-centred care to the residents with dementia and this showed throughout our observation. There were many examples of poor practice such as ignoring people, isolating people and laughing about residents with dementia with other, more able residents. There were very few times during this observation when the residents with dementia showed positive mood states, most people sat passively, slept or were angry, agitated or distressed.'*
> (inspection report)

We found a statistically significant correlation between the quality of staff training and development and people's well-being. In care homes where staff received good quality training that they could put into practice, people living in these homes experienced more positive mood states.

5.9 Conclusion

The findings of this report suggest that characteristics such as type of provider, size of home, or dementia registration, in and of themselves, do not guarantee quality care. Our study highlights leadership, support to staff, the culture of the home and staff training as key to providing good quality care.

Chapter 6

Conclusions

Key points:

- Direct observations help to understand the importance of good quality communication with staff. The significance of 'neutral' communications by staff on people's state of well-being is an especially important finding arising from this study.
- The findings support the importance of well-trained and supported staff working in homes committed to person-centred care, which may or may not be care homes that specialise in care for people with dementia.
- There are examples of excellent personalised care in this study but clearly this is not universal. CSCI issued 155 statutory requirements to 51 homes, ie half of all the homes inspected. In addition, 191 recommendations for improvements were made in areas such as care planning and staff training to the care homes inspected in this study. Where necessary, poorly performing homes were kept under scrutiny and appropriate action taken.
- Care homes should not be seen as a last resort. The quality of care should be such that they are indeed a positive care option for some people with dementia.
- Resources alone will not ensure quality care, but inconsistencies of funding present major challenges to recruiting well-trained staff.

6.1 People's perspective on living with dementia in a care home

A significant finding from this study is the negative effect of neutral communication on the feelings of people with dementia. The findings are valuable as they are obtained from direct work with people with dementia. The use of SOFI is an important development to ensure inspectors have ways around the communication difficulties faced by some people with dementia and it is their experiences that influence the overall assessment of the quality of care homes.

The systematic use of SOFI in all the thematic inspections has also highlighted its potential with other groups of people, in other settings, such as hospitals, and by other organisations, for example care providers.

One inspector commented:

> *'The value of the methodology should not be underestimated. It gives us insight into the interactions between staff and people using services, training issues for staff, highlights their understanding and awareness of dementia and principles of social care and their value base and highlights any disparities between the mission statement of the organisation and where the manager is coming from and the day–to-day work of care staff.'*
> (inspection report)

6.2 Supporting good personalised care

Our findings do not suggest there is any particular type of home most likely to provide good personalised care. The majority of homes in both the top and poor performing homes in terms of interaction and communication were registered as care homes for people with dementia.

The findings of the study have underlined the importance of all direct care staff having skills in working with people with dementia, rather than just staff working in homes that specialise in the care of people with dementia. Staff need to have a strong concept of what it might feel like to live with dementia in a care home so that they use this perspective in all their work with people living in care homes.

Training alone is not enough and good leadership, staff support and a culture within a care home of respecting and treating people as individuals have been shown to be essential components of good quality care.

There are examples of excellent personalised care in this study but clearly this is not universal. CSCI issued 155 statutory requirements to 51 homes, ie half of all the homes inspected – these are illustrated in Table 3.

Table 3. Examples of statutory requirements issued during the thematic inspection

Issue	Number of requirements	Number of care homes
Information	16	16
Service user plan	39	31
Health care	6	5
Privacy and dignity	21	18
Social contact and activities	24	24
Staff complement	10	10
Staff training	21	21

CSCI also made 191 recommendations for improvements to the care homes inspected in this study. Where necessary, poorly performing homes were kept under scrutiny and appropriate action taken.

6.3 Stakeholder views

When we presented our early findings to groups of stakeholders, a number of issues were raised. The remaining sections of this chapter draw upon these discussions.

a) Personalised care and care homes

The negative image of care homes and the perception of these being the last resort concerned many people. This adversely affected the recruitment of staff, achieving the right atmosphere and providing good personalised care.

Currently it was felt that social workers were under great pressure to 'close cases' by moving people into care homes quickly and those people without council support, largely people paying for their own care, were making what is essentially a 'distress purchase'.

b) The quality of training

Good dementia care training of consistent quality was seen as a priority. Many felt there should be National Minimum Standards for dementia care training, regarding both content and the amount of training a staff member should receive. Some people therefore called for national benchmarking for training.

There were also concerns that training should be affordable and accessible to all care providers.

People with dementia and their carers discussed some practical steps that may help to develop the skills of the care home workforce. One idea discussed was a 'buddying' system.

> *'Two care assistants to work together and monitor each other rather than the management. Follow-up meetings would be the pairs coming together and discussing what they've discovered about each other which has worked in practice.'*
> (people with dementia and carers' group discussion)

c) Funding

Inconsistencies in the funding of care homes were seen as a major underlying problem. These include:

- where people 'improve' because they have responded well to good quality care, fees may be reduced and care providers effectively feel penalised for doing a good job
- significant geographical differences in funding levels across councils and primary care trusts.

> *'In one county people with dementia get a higher rate of funding for residential care but not for nursing care, in another county this may be the other way round.'*
> (policy makers' group discussion)

There were concerns that people with dementia may have no choice in the care home they go to live in. Councils or primary care trusts may refuse to meet the fees of their chosen home.

6.4 Messages for improved practice

The examples of excellent, individualised care described in the main report are not yet experienced by everyone. Clearly, there is much more to be done to improve the quality of care for people living with dementia in care homes. Action is needed urgently so that all care homes can genuinely be a positive care option for people with dementia.

Care home managers need to provide leadership, home ethos, staff support and training to ensure excellent personalised care; and to develop ways of assessing the well-being of the people with dementia they are caring for.

Local councils and primary care trusts need to procure services at a price that allow for the one-to-one communication and trained staff essential to people's quality of life and well-being.

The new regulator, the Care Quality Commission, needs to ensure that people's experiences are at the heart of their work and to support further development of SOFI and similar tools.

Part Two

Putting people's experiences at the centre of regulatory inspection

Chapter 7

Using 'SOFI' to capture people's experiences of care homes

Key points:

- CSCI's modern inspection activity is focused upon the experiences of people using the service and the outcomes for them.
- A Short Observational Framework for Inspection (SOFI) has been developed and is jointly owned under a copyright agreement by CSCI and The University of Bradford to capture, in a systematic way, the experience of care for people who use services who would otherwise be unable to communicate this to an inspector.
- SOFI builds on dementia care mapping, which is internationally recognised as a powerful way of evaluating the quality of care from the perspective of the person with dementia.
- SOFI is a methodology in development. It allows inspectors to understand better the experiences of people with communication difficulties and contributes to an overall assessment of the care home. SOFI findings are used alongside other forms of evidence to reach final decisions.
- SOFI provides a consistent approach for inspectors to make observations about care as well as a robust framework for making judgements about the quality of care for people with dementia.

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- SOFI involves observing the experience of care for up to five people over two hours of continuous observation in communal areas of the home. Inspectors usually include the lunchtime period.
- CSCI inspectors use SOFI to observe people's general state of emotional well-being, their levels of engagement with others, and staff interaction with people living in the home.

7.1 CSCI's approach to regulation

Like everyone else, people who rely on social care, whether in care homes, other 'institutions', or in their own homes, tell us they want services and service personnel to keep them safe, offer choice and control, promote their independence and relationships with others and preserve their dignity, individuality and privacy. These are the qualities by which all services should be judged.

CSCI has modernised the regulation of social care services. This includes how CSCI better reflects the experience of people, making our reports more accessible, making use of different types of information about what is really happening in the services we regulate and recognising that some services need much more attention than others. CSCI has implemented good regulation principles, namely that regulation should be:

- proportionate
- accountable
- consistent
- transparent
- targeted

and that it

- puts the people who use social care services at the centre of our judgement about the quality of the services they receive.

The principles of our new methodology, called *Inspecting for Better Lives*, ensures that our inspection activity is risk based and targeted appropriately. Thus, where we have sufficient evidence that a service is well managed and that the people using

it are achieving their desired outcomes and are kept safe, then we do not need to inspect as often.

Our inspection activity is focused upon the experiences of people using the service and the outcomes for them. Putting people at the heart of our work is a fundamental element of our approach to regulation. Our special approaches include:

- engaging people who use services as 'experts by experience' as members of the inspection team to gather evidence on inspection[51]
- having a link with someone living in the home to help inspectors to gather people's experiences
- surveys to help people using the service and other stakeholders
- using the Short Observational Framework for Inspection (SOFI) as part of key inspections of services where there are a significant number of people with communication difficulties.

7.2 Short Observational Framework for Inspection: SOFI

SOFI was developed by CSCI and The University of Bradford, in 2006[52]. The aim of SOFI was to try and capture, in a systematic way, the experience of care for people who use services who would otherwise be unable to communicate this to an inspector.

SOFI builds on Dementia Care Mapping, developed in the late 1980s and now internationally recognised as a powerful way of evaluating the quality of care from the perspective of the person with dementia[53, 54].

SOFI has built on the experience of Dementia Care Mapping and the inspection of care homes to develop a tool that evaluates the mood and engagement of people using services and staff communications that enhance or undermine people's sense of well-being.[55] Dementia Care Mapping is a more complex tool than SOFI. Observations usually take place over a longer period of time and it provides much more in-depth

51 Experts by experience are people of all ages, with different impairments and from diverse cultural backgrounds who have experience of using social care services. An expert by experience will take part in an inspection and talk to the people who use the care service. They will look at what happens in the service, take some notes, talk to the inspector and write a report about what they have found.
52 SOFI is jointly owned by CSCI and The University of Bradford. The tool cannot be used by other agencies without the written permission of both CSCI and The University of Bradford.
53 Kitwood T (1992) A new approach to the evaluation of dementia care. *Journal of Advances in Health and Nursing Care* 1(5): 41-60.
54 Brooker D (2005) Dementia Care Mapping (DCM): a review of the research literature. *Gerontologist,* 45(1): 11-18.
55 Brooker D (2007). *Person Centred Dementia Care: making services better*. London: Jessica Kingsley.

information about individuals to be used in care planning. SOFI is less intensive as it is designed to be used as part of the inspection process.

SOFI, like Dementia Care Mapping, is based on person-centred approaches to care and involves:

- Valuing the lives of people and those who care for them; promoting their citizenship rights and entitlements regardless of age or cognitive ability.
- Treating people as individuals; appreciating that all people have a unique history and personality, physical and mental heath and social and economic resources.
- Looking at the world from the perspective of the person using the service and listening to their 'voice'.
- Recognising that all human life is grounded in relationships; that people with communication disabilities need an enriched social environment to help them form and maintain these relationships.

Since December 2006 SOFI has been used as part of CSCI's inspection methodology in care homes for older people where there are a significant number of people with dementia. There are over 600 CSCI inspectors out of a total of 807 who are trained to use SOFI throughout England. All inspectors who use SOFI undergo an intensive two-day training programme to ensure their competence with the tool. Whilst this study focuses on people with dementia, SOFI can also be used when inspecting services for people with learning difficulties.[56]

7.3 Using SOFI alongside other inspection evidence

It is important to recognise that SOFI is a CSCI methodology in development. SOFI observations are not the only source of evidence upon which inspectors base their judgments. The SOFI findings give a snapshot of care, as experienced by people using the service, and are used alongside other information collected during the inspection process. This includes speaking with staff and reviewing care plans, policies and procedures. SOFI observations often raise questions for inspectors about care practices in the home, which are followed up using other sources of evidence.

56 Commission for Social Care Inspection (2007). *Guidance for inspectors: Short Observational Framework for Inspection*. London: Commission for Social Care Inspection.

7.4 How observations are carried out

SOFI involves observing the experience of care for up to five people. Up to two hours of continuous observation takes place in communal areas of the home, such as lounges, dining rooms and corridors. Observations do not take place in bathrooms or in people's bedrooms.

The inspector introduces themselves to people living in the home and visitors before they start the observation and explain what they will be doing. If inspectors see that their presence is causing any distress to people, they attempt to allay any fears. If the person cannot be reassured then the inspector will carry out the SOFI observations elsewhere or may decide not to use SOFI as part of that inspection. Our experience using SOFI is that people rarely seem to mind that we are observing the care they receive and are pleased that someone is taking an interest in their well-being.

7.5 Inspectors' presence affecting people's actions

We know that when care staff are being observed they will try to improve their performance. However, experience from dementia care mapping[57, 58] and from feedback from inspectors using SOFI is that it does not take long for care staff to forget about the observer and to revert to usual patterns of behaviour.

When care is observed to be good using SOFI, we see these positive patterns throughout the two hours of observation. But equally we find that staff cannot usually overcompensate by sustaining improved patterns of performance over a two hour period when care is not usually of this standard, especially during busy lunchtimes.

7.6 Using SOFI as a lever for improvement

Inspectors use findings from the observations and feed these back to the people who have been observed, care staff and managers. Detailed findings based on SOFI observations have been used to help services improve their care.

Enforcement action is the legal action taken by CSCI when a care home persistently fails to comply with the law or provides unsafe care. It can range from immediate statutory requirements being issued to cancellation of registration in extreme cases.

57 The University of Bradford (2005). *DCM 8 user's manual*. Bradford: The University of Bradford.
58 Brooker D and Surr C (2005). *Dementia care mapping: principles and practice*. Bradford: The University of Bradford.

SOFI can be used as evidence for enforcement and when special enforcement teams are brought in.

7.7 Collecting data using the SOFI

SOFI is a very detailed tool and the Commission has published guidance on its use.[59] It involves a two-hour continuous period of observation usually of five people. Inspectors make a recording every five minutes for each person they are observing. Each five-minute period is called a timeframe. For each timeframe the inspector makes a judgement about three domains:

(i) **General state of observable emotional well-being**, recorded as:

- **Positive**: the person is happy and relaxed.
- **Passive**: there are no signs of positive or negative mood.
- **Negative**: the person is distressed or agitated.
- **Withdrawn**: the person is disengaged and out of contact with the world around them.
- **Asleep**: the person is asleep.

The inspector records the most positive and active level of well-being they have observed during each timeframe if more than one type is observed.

(ii) **Level of engagement** that the person shows:

- **With people**: including staff, visitors, other people living in the home.
- **With animals**: many care homes have pets that can be a great source of enjoyment.
- **In a task or activity**: such as eating a meal, walking, looking at a magazine.
- **With an object**: for example holding an object, folding a piece of paper.

The inspector records each episode of engagement that occurs within each timeframe.

(iii) **Style of staff interaction and communication with people living in the home**, whether:

- **Positive**: including warm, supportive, friendly and caring approaches.

59 Commission for Social Care Inspection (2007). *Guidance for inspectors: Short Observational Framework for Inspection*. London: Commission for Social Care Inspection.

- **Neutral**: task orientated questions such as 'do you want a drink?'
- **Negative**: for example, cold or disrespectful comments that undermine people's well-being or treating people like children.

The inspector records each interaction. In making a judgement about the category of interaction, inspectors take both verbal and non-verbal content into account.

SOFI provides a structured framework to assist inspectors in making and recording observations and a consistent approach for making judgements about the quality of care for people with dementia.

7.8 Example analysis of SOFI data

The SOFI data is invaluable in helping inspectors to make judgements about the quality of care and more in-depth analyses of SOFI data can help to draw out trends and patterns. Three examples of the kinds of findings that SOFI can generate are presented in the remainder of this chapter. These findings are based on the analysis of SOFI data alone and have not been triangulated with other sources of evidence which normally make up inspectors' overall judgements about services. It is these kinds of trends and patterns that inspectors use to prompt further questions about the care home.

(i) Analysis of how people spend their time

Typically, people in our study were doing something either alone or with someone else during 73% of the timeframes[60]. There was a lot of variation in how active people were but overall this was an active time of day – most of the observations took place over lunchtime. Table 4 shows that only three people spent less than 10% of their time engaged, while the overwhelming majority of 424 people (53%) spent over 75% of their time engaged.

Table 4: Proportion of time people spent engaged

Average proportion of time people spent engaged	Percentage of people
Less than 10% of their time	1%
11–25% of their time	13%
26–50% of their time	16%
51–75% of their time	27%
76–100% of their time	53%

60 A timeframe is a period of five minutes.

It is worth noting that even during busy times of day, 57 (14%) people spent less than 30 minutes of their time engaged with the world about them. These low levels of engagement were not just confined to a few homes. 10% of inspected homes had within them some people who spent 25% or less of their time engaging with anything or anyone over the lunchtime period. People who spent the least time engaged were those with a higher level of communication or other impairments.

The kinds of activities people were most likely to be involved in are illustrated in Table 5.

Table 5: How people tend to spend their time

Level of engagement	Percentage of timeframes where this occurred
Involvement in some task or activity	45%
Communicating with staff	38%
No involvement or engagement with others or any activity	27%
Communicating with other people living in the home	9%
Holding or touching things such as cushions, table items, etc	6%
Communicating with visitors	2%

(ii) Analysis of people's levels of well-being

Previous studies indicate that people in care homes spend long periods of the day in passive or withdrawn and sleepy states.[61] Given that we observed over a lunchtime when people were relatively active, we expected that we would see better levels of well-being at this time of day.

Typically, people observed in a care home over the two-hour lunch period showed:

- Signs of being relaxed and happy in 45% of timeframes (positive mood).
- No signs of negative or positive mood but were watching what was going on in 38% of timeframes (passive mood).
- Visible upset or distress or being withdrawn into themselves for 7% of timeframes (negative and withdrawn mood).

61 Help the Aged in partnership with the National Care Forum and the National Care Homes Research and Development Forum (2007). *My home life. Quality of life in care homes. A review of the literature*. London: Help the Aged.

- They were asleep for 10% of timeframes.

There was a wide variety in the different levels of well-being that people living in care homes displayed. From Table 6 we can see that around 80 people (19%) spent over 75% of their observed timeframes in a happy or relaxed state. In contrast 68 people (16%) spent less than 10% of their time displaying signs of happiness or relaxation (Table 7).

Table 6: Observed happy and relaxed

Proportion of timeframes people spent in a positive mood state	Percentage of people
Less than 10% of their time	16%
11–25% of their time	15%
26–50% of their time	29%
51–75% of their time	21%
76–100% of their time	19%

Table 7: Observed distress

Proportion of time people spent in observed distress	Percentage of people
Less than 10% of their time	89%
11–25% of their time	6%
26–50% of their time	3%
51–75% of their time	1%
76–100% of their time	0%

Three individuals spent more than 50% of their time showing signs of obvious distress. The overwhelming majority of 380 individuals (89%) spent less than 10% displaying signs of distress. These individuals were spread across the different homes generally rather than being clustered in a small number of homes.

Four people spent between 51% and 75% of their time in complete withdrawal. The majority of 371 people (87%) spent less than 10% of their time withdrawn during the observation period (Table 8).

Table 8: Proportion of timeframes people spent withdrawn

Proportion of time people spent withdrawn	Percentage of people
Less than 10% of their time	87%
11–25% of their time	9%
26–50% of their time	3%
51–75% of their time	1%
76–100% of their time	0%

Further analysis of the time people spent in a withdrawn mood showed that people experienced withdrawn mood at least some of the time in 51 of the homes. However, in 15 homes 50 to 100% of people observed experienced some proportion of their time in a withdrawn mood state during the lunchtime period. This suggests there was a clustering of withdrawn behaviours in some of the homes.

(iii) Analysis of communication

We examined the amount of communication between staff and people being observed. We found no communication between staff and people living in the home in 56% of all the timeframes observed. Communication occurred in 44% of the timeframes.

The proportion of time people spent communicating with staff ranged from:

- 11 people (3%) communicated with staff in less than 10% of the timeframes they were observed for, to
- 23 people (5%) communicated with staff in over 75% of the timeframes they were observed for (Table 9).

Table 9: Proportion of time in which there was communication with staff

Proportion of timeframes people spent communicating with staff	Percentage of people
Less than 10% of their time	3%
11–25% of their time	15%
26–50% of their time	49%
51–75% of their time	23%
76–100% of their time	5%

Nearly one-quarter (23) of homes had low levels of communication generally. This means all people observed spent 50% or less of their timeframes communicating with staff. The majority of homes had some people who received low amounts of staff communication alongside others who experienced much more. We also identified a small cluster of seven homes that achieved high levels of communication with people – 80% or more of observed people living in the home spending more than 50% of their time frames interacting with staff.

The quality of communications varied:

- 64% of all communications were positive communication and judged as enhancing to people's well-being
- 28% of all communications were neutral, which was often just a simple question or instruction
- 8% were negative – these were communications that were judged to be demeaning or disrespectful to the person.

Positive communications

There is a fairly even spread in the proportion of positive communications that people with dementia experienced. At the low end, 24 people (5%) experienced a positive staff communication in less than 10% of all their communication with staff. At the upper end, 157 people (37%) experienced a positive staff communication in over 75% of all communications with staff. Out of all 424 people observed, 80 people (19%) did not have any negative or neutral communication with. However 344 people (81%) experienced some communication with staff that are potentially damaging to well-being.

Out of 100 care homes inspected, we identified 33 homes where on average between 76% and 100% of communications with staff were positive. In contrast, we found only two homes where, on average, people experienced a positive communication in less than 10% of their communications with staff.

- In 82 homes, everyone experienced at least one positive communication during the two-hour observation. These communications included verbal and non-verbal forms of communication.
- In 18 care homes there were one or more people who experienced no positive communications. In one of these homes none of the people observed experienced a positive communication from staff during the observation period.

- There was a small minority (23 people, 5%) of people who had no positive communication with staff during the time they were observed.

We found a strong statistically significant relationship between positive staff communications and positive state of well-being for people living in the homes.

Communicating in a disrespectful and negative way

Three hundred (70%) individuals experienced less than 10% of their communications with staff as negative. Fifteen people (4%) experienced negative staff communication in over half of their communiaction with staff.

We examined these data by care homes and found:

- In 67% of homes, people on average experienced negative communication in less than 10% of all their contacts with staff.
- In 33% of homes, people on average experienced negative communications in 11 to 50% of all their contacts with staff.
- The individuals who experienced negative staff communication in 50% or more of their contacts with staff were spread over 11 care homes. In one home, four of the five individuals observed experienced negative communications in over half of all their communications with staff.

Thus, there appeared to be a clustering of disrespectful and negative communication in some homes.

There was a strong correlation between high levels of negative communications and low levels of positive mood. Again, this underlines the importance of how staff interact with people. It is not just an issue of being disrespectful when negative communications occur; it has a direct observable effect on people's well-being.

Communicating in 'neutral' ways

SOFI refers to 'neutral' communications. These occur when staff focus on something that needs to be done and typically lack empathy and warmth. Examples of neutral communications include asking someone swiftly if they need the toilet or offering meal choices.

Twenty-six people (2%) experienced these types of communications in 76 to 100% of their communications with staff. These were spread over 19 different care homes. 123 people only experienced a neutral communication in less than 10% of all their communications with staff. They were spread over 57 care homes.

Table 10 shows that in 18 care homes neutral communications were experienced on average in less than 10% of all communications. In 2% of the homes the average percentage of staff communications with people that were neutral was between 76% and 100%.

Table 10: Average number of neutral communications by care homes

Neutral communications per home	Percentage of care homes
Less than 10% of their time	18%
11–25% of their time	26%
26–50% of their time	39%
51–75% of their time	15%
76–100% of their time	2%

Our analyses of SOFI data demonstrate a strong statistically significant correlation between high levels of neutral communications and low levels of positive mood. Neutral communications appear to have a negative effect on the mood of people with dementia living in care homes.

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Alongside CSCI staff, Dawn Brooker, Claire Surr and Andy Scally from The University of Bradford helped to prepare this report.

Responsibility for this final report rests with CSCI.

Notes

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