See me, not just the dementia

Understanding people's experiences of living in a care home

Summary and electronic version of full report

June 2008

Copyright – This publication may be reproduced in whole or in part (with the exception of the multi media materials), free of charge, in any format or medium provided that no payment, charge or fee will be levied for the provision of information that is otherwise available free of charge directly from CSCI. This consent is subject to the material being reproduced accurately and on proviso that it is not used in a derogatory manner or misleading context. The material should be acknowledged as Commission for Social Care Inspection (CSCI) copyright, with the title and date of publication of the document specified.

Multi media materials contained within the publication should not be reproduced without specific permission.

Short Observational Framework for Inspection (SOFI)
© 2006 The University of Bradford & The Commission for Social Care Inspection. No part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, without a licence to do so from the Commission for Social Care Inspection and The University of Bradford.

New format for this report

The full report is available in standard printed form. It is also available as an interactive CD-ROM and is attached to the back of this summary. This new electronic format is a 'pilot' version, it includes filmed interviews and good practice discussions. Please ensure your computer system supports the required software as detailed on the front of the CD.

All versions can be ordered free from:
csci@accessplus.co.uk or **0870 240 7535**.

Photography, page 6, 14 and cover: www.JohnBirdsall.co.uk

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 study focuses on the experiences of people with dementia living in care homes and the quality of care provided. Unlike most studies that have relied on the views of staff and carers, this report is based on the findings from 100 thematic inspections of care homes which examined the experiences of 424 people with moderate to advanced stages of dementia using the new observational process (the Short Observational Framework for Inspection – SOFI). Inspectors use findings from the observations with other sources of evidence collected during inspection to make judgements about how well services are meeting people’s individual needs. These findings are fed back to care home providers to support improvements.

There are growing numbers of people living with dementia in care homes, currently estimated at 244,000 people. Dementia is a progressive illness that affects people in different ways and is usually accompanied by an increasing need for assistance and support with daily living and personal care. This requires a careful and sensitive approach to the provision of care.

Government policy promotes personalised care to enhance personal dignity and respect which is about understanding fully people’s lives, hopes and expectations. Providing care to people with dementia, often in the later stages of their lives, can be demanding. Excellent care based on good evidence of what works does exist but Government has

1 Quotation attributed to the late Tom Kitwood.

acknowledged the evidence of a series of reports that good practice is not yet universal. It is developing a national strategy to improve support to people with dementia and their carers.

The focus of our study is on whether care is personalised and enhances people's dignity and respect, a key objective of Government policy set out in the joint concordat *Putting People First*.

About the study

A broad range of care homes were involved, both specialist and non-specialist, excluding those seriously underperforming and subject to enforcement action. A large number of the 100 homes, 82, had been rated previously as adequate or good. Twelve homes had been rated excellent.

In total, inspectors observed 424 people using the SOFI. 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.

The thematic inspections in this study 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?

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

Are my wishes respected and my views taken into account?

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, 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. The best care plans are clearly and sensitively written with detailed information regarding 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)

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. In some homes we found 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)

We found 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.

However, poorly written plans that are not holistic, and do not focus on people's abilities, risk being translated into equally poor practice. Over one third of homes inspected did not meet statutory requirements[2] in terms of the quality of their care planning. In some homes we found staff were detached from the care planning process.

2 Statutory requirements are actions the care services must take by law in order to comply with the regulations within a reasonable time.

‘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 they may have little background information on which to judge what someone’s wishes and preferences might be.

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

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. 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.

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. We found that people who were least engaged were those with the most severe communication problems and disabilities. In some circumstances this may also have been related to long-standing mental health problems such as depression. However, a clustering of these withdrawn behaviours was found in 15 out of the 100 homes. This suggests that other environmental factors, such as a poor culture of care, may have been at work here.

We also found excellent examples of care offered with warmth, understanding and tolerance. When there is an opportunity to be engaged and involved then the vast majority of people with dementia in care homes enjoy the 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.

But 21 requirements were given to 18 of 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.

‘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)

On occasions, we saw some staff talking over people to other members of staff, as they assisted them to the toilet.
(inspection report)

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 communications that leave people with dementia feeling distressed and withdrawn but also 'neutral' styles of communication. This is where staff focus on something that needs to be done and typically lacks empathy and warmth.

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 a family carer)

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

Family carers often struggle with their own feelings when the person they care for moves into a home. 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.

Care staff can feel challenged and compromised by 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 attend clubs or faith centres. 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. Detailed analysis of the observations found 177 people (42%) spent no time at all in contact with other people living in the home during a time of the day when higher levels of interaction might have been expected.

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. When care homes make an effort to welcome and maintain links with others, people living in the homes demonstrate higher levels of well-being.

Supporting positive practice

The study demonstrates that the quality of staff communication with people with dementia has a major impact on their quality of life. 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.

To understand the factors that support those homes that encourage good and proactive communication with people, we compared the characteristics of the top band of homes performing well in communication with those in the lowest band.

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. Some 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. However, inspectors issued 21 requirements to 21 care homes on staff training. There were also 28 recommendations[3] about staff training. Our analysis showed a statistically significant relationship between staff training and development and people's well-being.

Conclusions

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 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.

3 Recommendations for improvements are 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.

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 1.

Table 1. 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.

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 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.

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

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

CSCI's modern inspection activity is focused upon the experiences of people using the service and the outcomes for them.

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 in contributing this to an overall assessment of the care home and improvements in care. It is important to note that 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. It 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 communication and interaction with people living in the home.

How to contact CSCI

Commission for Social Care Inspection
33 Greycoat Street
London SW1P 2QF

Helpline:
Telephone: 0845 015 0120 or 0191 233 3323
Email: enquiries@csci.gsi.gov.uk
www.csci.org.uk/professional

We want people to be able to access this information.
If you would like a copy of the summary in a different format or language please contact our helpline or go to our website.

Get monthly updates on news from CSCI – sign up to our email newsletter www.csci.org.uk/professional

CSCI-SSR-154-3500-CWP-062008
CSCI-230

This document is printed on 50:50 recycled stock. When you have finished with it please reuse it by passing it to someone else, thank you.