

CRACKS IN THE PATHWAY

People's experiences of dementia care as
they move between care homes and hospitals

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The photographic illustrations used in this report are courtesy of Ian Donaghy from his book *Dear Dementia*.

CONTENTS

➤ 1. FOREWORD	3
➤ 2. SUMMARY	5
➤ 3. INTRODUCTION	10
➤ 4. FINDINGS	16
4.1 Assessment of care needs	16
4.1.1 Assessment process	17
4.1.2 Pain management	19
4.2 Planning and delivery of care	20
4.2.1 Clinical guidelines, best practice	20
4.2.2 Management of behaviour that challenges	21
4.2.3 Urinary tract infections	22
4.2.4 Falls	23
4.2.5 Meaningful activity and occupation	24
4.2.6 Privacy and dignity	25
4.2.7 Environment	27
4.3 Providers working together	29
4.3.1 Access to health and social care support	29
4.3.2 Sharing information between care homes and hospitals	30
4.4 Staffing	33
4.4.1 Lead roles	33
4.4.2 Training and support	33
4.4.3 Numbers of staff	34
4.5 Involvement	36
4.5.1 Choices and decisions about care	36
4.5.2 Involvement of family, friends and carers	37
4.5.3 Diversity and inclusion	38
4.6 Monitoring the quality of care	38
4.6.1 Culture and leadership	38
4.6.2 Monitoring quality and making improvements	39

> 5. OTHER FEEDBACK	42
<hr/>	
> 6. CONCLUSIONS AND NEXT STEPS	44
Actions CQC will take	44
<hr/>	
> 7. REFERENCES	45
<hr/>	
> APPENDICES	45
Appendix 1: Methodology	45
Sample selection	45
The inspections	46
Inspection teams	46
Involving people and requesting feedback	46
Appendix 2: Further reading	47
<hr/>	
> ACKNOWLEDGEMENTS	48



1. FOREWORD

Each year the number of people living with dementia is growing. Most of the 400,000 older people living in care homes have dementia or a similar impairment and an estimated 40% of people over the age of 65 in hospital beds will be living with dementia. This large and increasing number of people must not be ignored.

During 2013 and 2014, the Care Quality Commission (CQC) carried out a thematic review of the care of people living with dementia as they moved between care homes and acute hospitals.

We found more good care than poor care in the care homes and hospitals our inspectors visited, but the quality of care for people living with dementia varies greatly. It is likely that someone living with dementia will experience poor care at some point while living in a care home or being treated in hospital. This unacceptable situation cannot continue. People living with dementia, their families and carers have every right to be treated with respect, dignity and compassion.

At CQC we are determined to play our part in making sure that people living with dementia receive care that is safe, effective, compassionate and high-quality. We will hold services to account in our regulation of care homes and hospitals by setting clear standards, inspecting against those standards, sharing our judgments on how services are performing and taking action to encourage services to improve where that is necessary.

As the report makes clear, there are some examples of excellent care across hospitals and care homes in England. These are services that recognise that a personalised approach is the key to high-quality care for people living with dementia. They know that care must be

delivered by knowledgeable and skilled staff who have time for the individual needs of the person living with dementia. They make sure that comprehensive assessments are carried out, updated and then shared when someone moves between services.

Where we find services like this we find an open and transparent culture, focused on the needs of individuals, willing to look for innovative and creative solutions, seeking out good practice to adopt and constantly keeping its own performance under review.

We want all services to be like this, but sadly we know that is not always the case. We are committed to driving changes across the health and care system to improve the lives of people living with dementia. Where poor dementia care exists, we are finding it and taking action and we will continue to do so. We recognise that there is more we can do and some specific actions we will take include:

- Appointing a new national specialist adviser for dementia care.
- Training inspectors across all inspecting teams to understand what good dementia care looks like so that their judgments of the performance of providers are consistent and robust.
- Adding a separate section to hospital inspection reports that shows how well the hospital cares for people living with dementia.

Also, the changes we are already making to rate services as outstanding, good, requires improvement or inadequate will encourage services to improve and provide better information for people making choices about care.

Although this review focuses on care homes and acute hospitals, improving care for people living with dementia goes beyond these institutional boundaries. It is a shared endeavour involving government departments, commissioners, regulators and improvement agencies. We all need to see this as a priority and we need to work well together.

Throughout this report we have used the words of people living with dementia who have described their experience of care, alongside the observations of our inspectors. These words paint a powerful picture of the need for change and what can be achieved. These words will also drive our commitment to honour the rights of people living with dementia and we hope they will provide a powerful impetus for others as well.



Professor Sir Mike Richards
Chief Inspector of Hospitals



Andrea Sutcliffe
Chief Inspector of Adult Social Care



2. SUMMARY

What we found

Overall we found more good care than poor in the care homes and hospitals we visited, but the quality of care for people with dementia varies greatly and it is likely that they will experience poor care at some point along their care pathway. Clear guidance has been available for years, but improvements in care are still needed and overdue.

When done well, care is delivered by passionate, knowledgeable and skilled staff, working in organisations that are committed to providing the best quality of care. Good dementia care puts the person at the centre of their care and considers how their dementia affects them. This approach has a significant and positive impact on the wellbeing and quality of life for people with dementia and their families.

Q "When I was admitted to the care home, staff considered the information from the placement team, carried out their own assessment and spoke with me and my family. They found out about my life history and my interests and started to get to know me as a person."



Throughout the report we have used colour to differentiate between the words of **people living with dementia and their families** (pink), **our inspectors** (blue) and **providers** (green).

Across more than 90% of care homes and hospitals visited, we found aspects of variable or poor care¹

➤ Assessment of care needs

In 29% of care homes and 56% of hospitals we found aspects of variable or poor care regarding how a person's needs were assessed.



➤ Providers working together

In 27% of care homes and 22% of hospitals we found aspects of variable or poor care regarding the arrangements for how they shared information when people moved between services.



➤ Involvement

In 33% of care homes and 61% of hospitals we found aspects of variable or poor care regarding people or their families and carers not being involved in decisions about their care and choices about how to spend their time.



➤ Planning and delivery of care

In 34% of care homes and 42% of hospitals we found aspects of variable or poor care regarding how the care met people's physical and mental health and emotional and social needs.



➤ Staffing

In 27% of care homes and 56% of hospitals we found aspects of variable or poor care regarding staff's understanding and knowledge of dementia care.



➤ Monitoring the quality of care

In 37% of care homes and 28% of hospitals, we found aspects of variable or poor practice in the way providers monitored the quality of dementia care.



1. We reviewed the inspection reports for the care homes and hospitals we visited and identified aspects of good, poor or variable practice for each of the pathway stages and each of the factors considered in this report.

Good care helps people to maintain their health and wellbeing and avoid unnecessary admissions to hospital or prolonged lengths of stay in acute care. It reduces the risk of anxiety and distress that people can experience when their care environment and routine is changed.

Failing to recognise and meet the needs of people with dementia (at all stages of their care pathway) results in people in vulnerable circumstances receiving, or being at risk of receiving, poor care. People with dementia have the right to expect good care and the variability in the quality of care they experience is unacceptable.

Ω "Nobody asking or listening to what I say... people treating me like I cannot think at all anymore. Feeling so disempowered that I feel like nothing."

This themed inspection looked at people's experiences of dementia care as they moved between care homes and acute hospitals. We inspected 129 care homes and 20 acute hospitals, looking at how people's care needs

were assessed, how the care was planned and delivered, how providers worked together, and how providers monitored the quality of their care. As part of our inspections, we asked people and their families to tell us about their experiences of care and what was most important to them.

Ω "When I was in pain I was unable to tell staff about this. Sometimes this meant I didn't get any pain relief for a long time."

We have identified the stages on the care pathway and the factors that have the most impact on the quality of care when people move between providers. We found variability in the quality of care at each stage on the pathway (see page 6). While many issues were common to hospitals and care homes, some were more pronounced in one sector than the other. For example, hospitals may need to focus more on the whole person when making assessments, rather than just their physical needs, whereas care homes may need to focus on making better use of existing guidance to support their delivery of care.

Assessment of care needs

The needs of people with dementia are not always adequately assessed to ensure that they are met at all stages of their care pathway. Assessments do not always consider how the type of dementia affects a person in their daily life, or identify how staff can support them.

In hospitals, assessments focused on a person's physical health needs, with less consideration given to mental health, emotional and social needs. Assessments to identify and manage pain are variable, putting people with dementia at risk of experiencing pain unnecessarily.

Planning and delivery of care

Available guidance is not used effectively to support dementia care. Where changes in a person's condition or behaviour were not identified or managed appropriately, they were more at risk of poor care. Personalisation,

putting people at the centre of their own care, helps improve the experiences of people with dementia. Failure to manage known risk factors, including falls and urinary tract infections, can lead to avoidable admissions to hospital.

Q "I was able to find my room, it had a blue door and signs with pictures on helped me to find the bathroom."

The environment has a significant impact on a person's wellbeing. Environmental changes and having different people looking after them can be particularly distressing to people with dementia. Affording privacy, dignity and respect to people with dementia is part of helping to maintain their personal identity.

Providers working together to deliver care

Arrangements to share information between care homes and hospitals are not good enough. Often, relevant information is not shared or acted on when people are moved between care homes and hospitals. As a result, their needs are not met.

Q "In hospital, I was moved from one ward to another. My 'This is Me' document was lost and staff did not ask me or my family about my dementia."

Access to support from a range of health and social care professionals is required to maintain people's health and mental wellbeing while living in care homes and hospitals. Their involvement helps people to avoid unnecessary admissions to hospital and supports their discharge from hospital.

The voluntary and community sectors have a key role in supporting people with dementia and their families, friends and carers. Staff and providers could do more to signpost people to these services.

Staffing

There are not always enough well-supported and trained staff (and with the right values) to care for people with dementia. Not all staff are equipped to understand what good dementia care looks like. Some care is task-based and this ignores people's emotional and psychological care needs. Training for staff who care for people with dementia is not routinely evaluated for its impact on the care itself.

Q "I ate what was given to me, but sometimes I saw people eating other food I would have preferred."

People with dementia and their families told us that staff who understood their needs was the most important thing.

Involvement

Arrangements to make sure that people with dementia are supported to make decisions about their care are not effectively applied. Good care for people with dementia involves the family, friends and carers in decisions and choices about their care.

Monitoring the quality of care

A culture based on strong values supports good dementia care, but this is not yet established in all organisations. Providers are not routinely using systems to monitor effectively the quality of dementia care and inform improvements.

Q "I am not always able to make decisions for myself and the staff discussed what was in my best interest with my family and other people who know me well."

Conclusions

The quality of dementia care across providers is variable, and transitions between services need to be improved. People with dementia are likely to experience poor care at some point along their care pathway, but they have the right to expect good care and it is unacceptable that they should receive a variable quality of care.

Action CQC will take

- Appoint a new national specialist adviser for dementia care.
- Train inspectors across all inspecting teams to understand what good dementia care looks like so that their judgements of the performance of providers are consistent and robust.
- Include a separate section in hospital inspection reports that shows how well the hospital cares for people living with dementia.

Where to go for more help:

CQC website

www.cqc.org.uk

The Alzheimer's Society

www.alzheimers.org.uk

Dementia Action Alliance

www.dementiaaction.org.uk

Skills for Care

www.skillsforcare.com

Skills for Health

www.skillsforhealth.org.uk

Healthwatch England

www.healthwatch.co.uk

National Institute for Health and Care Excellence (NICE)

www.nice.org.uk

NHS Choices

www.nhs.uk

Social Care Institute for Excellence – Dementia Gateway

www.scie.org.uk/dementiagateway



3. INTRODUCTION

People living with dementia use all types of health and social care services, as well as community and voluntary services. They often receive care from a number of different providers and move between services as part of their care pathway.

In this programme of inspections, we focused on the quality of care people living with dementia received to help maintain their physical and mental health and wellbeing in care homes and hospitals. We looked at how the care provided can prevent unnecessary admission to hospital. We also considered how providers of care work together and how the quality of dementia care provided is monitored.

Good and poor experiences of care

Our inspection programme looked at the journey, or pathway of care, for someone with dementia who lives in a care home and as they were moved from the care home to the hospital and then back to the home. We considered the quality of care at a number of stages along this pathway.

We looked at the assessment of people's needs on admission to the care home, and how care was delivered to help them maintain their physical and mental health and wellbeing. We also considered how the care provided prevented admission to hospital.

For people admitted to hospital, we looked at how the care home and hospital worked together, including what information was shared. In hospital, we looked at how their dementia care needs, as well as their physical

health needs, were supported. Finally, we looked at the planning and management of a person's discharge from hospital.

Across the whole pathway we considered the training and support available to staff, the quality of care provided, and how people, together with their families, friends and carers, were involved in making decisions and choices about their care.

The following table contains personal quotations that illustrate both good and poor experiences of care for someone living with dementia. It describes care as they experienced it, from their admission to a care home, through admission to hospital, and finally discharge back to the care home. These examples are not based on findings from a single care home or hospital, but are a collation from our observations.

Poor experiences of care



Good experiences of care

CARE HOME

1. Assessment of care needs

When I was admitted to the care home, staff asked a few questions about my care. They didn't ask my family about my life history.



When I was admitted to the care home, staff considered the information from the placement team, carried out their own assessment and spoke with me and my family. They found out about my life history and my interests and started to get to know me as a person.



2. Planning and delivery of care

My care was not well documented and staff did not know that I preferred to be called Marge and eat in my room... that made me anxious and could cause me to become agitated and aggressive.

Changes in my behaviour and condition were not identified promptly. Sometimes I got angry and started shouting.

When I was in pain I was unable to tell staff about this. Sometimes this meant I didn't get any pain relief for a long time.

My care needs were written down and included all the relevant information so that people understood how to care for me. I was given information about the home and about my care. After a couple of weeks settling in, the staff updated my care plan.

In planning my care staff had considered best practice and national guidelines, including National Institute for Health and Care Excellence guidelines. My key worker had overall responsibility for my care.

My care needs were regularly assessed and when my behaviour or condition changed this was reassessed. My family were contacted about these changes.

My GP visited regularly and I saw the district nurse. They helped look after me when I was unwell.

Staff understood when I was in pain and used a specific tool to help assess this. They provided medication to manage my pain.

Poor experiences of care

Good experiences of care

CARE HOME

2. Planning and delivery of care

ENVIRONMENT

I found it difficult to find my way around the home or remember where my room was.

The corridor was very dark and the patterned carpet made me feel disorientated. I have fallen over a couple of times.

I was able to find my room, it had a blue door and signs with pictures on helped me to find the bathroom.

There was a crash mat by the side of my bed as I fell out of bed sometimes.

MEANINGFUL ACTIVITY AND OCCUPATION

I spent a lot of time sitting in the lounge with the television on. I felt bored much of the time.

There was one resident who got angry sometimes and started shouting. Staff were not there to help him and I felt anxious.

I spent my time doing things I enjoyed and involved in everyday activities. Staff treated me with dignity and respect, and told me what was happening and asked me what I wanted.



"I felt bored much of the time"



"Staff treated me with dignity and respect"

Poor experiences of care

Good experiences of care

CARE HOME

3. Staffing

I waited for a long time for someone to help me eat and go to bathroom.

There were enough staff to look after me. Staff had received training and they understood about how my dementia can affect me. They spent time with me.

4. Involvement

I ate what was given to me, but sometimes I saw people eating other food I would have preferred.

I liked spending time in the garden, but the door was kept locked.

The care home asked me and my family about my care and there were residents' meetings to discuss how things could be improved and address concerns.

I am not always able to make decisions for myself and the staff discussed what was in my best interest with my family and other people who know me well.

"Sometimes I saw people eating food I would have preferred"

"Staff discussed what was in my best interest with my family and other people who know me well"

5. Providers working together

ADMISSION TO HOSPITAL

I had a fall in the middle of the night and needed to be admitted to the hospital. Staff were unable to access the office to get my notes to go with me so the hospital would know about me.

I was unwell and needed to be admitted to hospital. A member of staff accompanied me to hospital and they took my 'This is Me' document, which had information about me.

Poor experiences of care



Good experiences of care

HOSPITAL

6. Assessment of care needs

I waited in A&E a long time before I was seen, and I felt scared and anxious in this new environment.

"I felt scared and anxious in this new environment"

On admission to hospital I was seen in A&E. I was looked after in a quiet and calm area. When my needs had been assessed, I was transferred to a ward. On the ward staff used my 'This is Me' document to understand my needs. There was a picture of a flower above my bed so that staff were aware of my dementia.

"I was looked after in a quiet and calm area"

7. Planning and delivery of care

In hospital, I was moved from one ward to another. My 'This is Me' document was lost and staff did not ask me or my family about my dementia.

The ward was very busy and noisy and I felt anxious and unsettled.

When I felt scared I could get frustrated and angry and start shouting and become aggressive. The nurses didn't know how to react and called security staff to the ward.

A dementia care pathway was used to manage my care, which was overseen by a named clinician.

Planning for discharge was started quickly.

My family were able to visit and were informed about my care.



Poor experiences of care

Good experiences of care

HOSPITAL

8. Providers working together

DISCHARGE TO CARE HOME

I was sent back to the care home late in the evening. The information that came with me said I needed to have some new medication. Staff didn't update my care plan to reflect this.

A few days later I had another fall and was readmitted to hospital.



When I was ready for discharge, I was able to stay on the ward rather than be moved to the discharge lounge. The manager from my care home visited me before I was discharged.

The hospital gave detailed information about me to give to the care home when I arrived home. The care home updated my records to reflect the changes indicated by the hospital and told staff about the changes to my care.



To make sure that people experience good care, providers need to have arrangements in place to monitor the quality of care.

This includes:

- Using guidelines that describe what good care looks like
- Identifying and investigating when things go wrong
- Listening to feedback from people.



4. FINDINGS

This section describes our findings at each of the key stages along the care pathway and the factors that affected the quality of care provided.

4.1 Assessment of care needs

Assessing the care needs of someone living with dementia can be complex, but it is essential to make sure that they receive the right support, care and treatment, including when they move between services. Many people living with dementia also have other medical conditions including diabetes, heart disease, Parkinson's disease, visual and hearing impairments. When assessing care needs, it is important to make sure that these conditions are managed appropriately. Failing to do this could lead to avoidable admissions to hospital.

There are different types of dementia, with Alzheimer's disease being the most common. Age is also a factor for all dementia types, with differing rates of onset. Early onset dementia is the term used to describe people under the age of 65 who are diagnosed with dementia. It is important that assessments consider the type of dementia and how this affects a person in their daily lives. In 29% of care homes and 56% of hospitals we visited, we found aspects of variable or poor practice where assessments were not comprehensive in identifying all of a person's care needs.

4.1.1 Assessment process

Assessing a person's health and social care needs is an important part of providing care in care homes and hospitals. Assessments must be made on admission to a service and then on a regular basis, or in response to changes in a person's circumstances. Involving the person and their families and carers is also important.

Good care involved comprehensive assessments that included information about a person's physical health, mental health, and their emotional and social needs. It also looked at assessments from a range of health and social care professionals, including psychologists and psychiatrists. Involving the person and their family was important to help understand, for example, how to meet their personal care needs, their dietary preferences, and whether and how they wished to practice their religion.

A manager of a care home told us:

Q "Listening to the person, families and friends is the starting block... you need to get to know the person. The priority is the person."

For people living with dementia, a good understanding of their life history creates a person-centred approach to their care. We saw good examples of assessments that found out about the person, including previous employment, significant events in their lives, their families and friends, and their hobbies and interests.

Q "We saw that people's written assessments included information about their life history... staff knew people well and understood the importance of their life history in [supporting] the person. For example, we heard a staff member talking with a person about their previous occupation as a nurse and their experience of the role. The assessment also asked people about their preferences of social activities. For example, whether they wished to join in group activities or have some one-to-one time allocated to them."

Dementia can affect people's behaviour and how they react, and understanding this is an important part of caring for this person. A good assessment considered how the diagnosis and type of dementia affected them in their daily lives, and suggested how staff could support them.

Q "We saw how supporting dementia was built into each care plan. For example, the night time care plan for one person reminded staff that the person had little concept of night and day, and needed to be reminded it was night time. It showed that if the person said they were 'hungry' at night it usually meant they needed to use the commode. The manager told us... staff might put dressing gowns on themselves to help people connect wearing a dressing gown with night time and going to bed."

However, we found that some people's needs were not being fully assessed, and that not all the aspects of caring for someone living with dementia were considered. This meant that care was not planned appropriately.

Q "There was a lack of focus on the person's diagnosis of dementia within the assessment process... The assessment did not look at the person's current level of functioning, for example, their independence in daily living skills, or their potential to develop skills. There was limited information... to show the effects of the diagnosis of dementia."

As part of our inspections of hospitals, we visited A&E departments as well as wards. We found that assessments in A&E only considered physical causes for patients displaying symptoms associated with dementia or delirium.

Most of the hospitals we inspected screened patients aged over 75 for possible signs of dementia. Following the screening, people were referred to their GP or a memory clinic for further assessment. This was done as part of the Commissioning for Quality and Innovation (CQUIN) framework and hospitals monitored how often the screening took place. However, we saw evidence that screening was not always completed, even though a referral was made.

Q "We found [that] one patient's care records contained three CQUIN screening forms. Their care records also showed that they had been referred to their GP while an inpatient at the hospital six months previously. This meant that although the patient had been screened three times and had been referred, they had not been assessed to have their dementia-related support needs met."

We found that hospital assessments for patients living with dementia focused on care of their physical needs. There was limited evidence to show that staff considered their emotional and psychological needs, and how this affected their mental health and wellbeing. Patients were not always considered as individuals in their care planning.

Documents such as 'This is Me' were being introduced into some hospitals. This is a practical tool to help people living with dementia tell staff about their needs, preferences, likes, dislikes and interests. However, their use varied, even between wards in the same hospital, and in some cases they were incomplete.

Q "We were told by staff on all wards that each patient with dementia had a document entitled 'Information about me to help you', which when completed would provide staff with additional information about the patient's likes and dislikes and what was important to them. We found that a small number of these documents had been completed but most had not, and staff told us that where patients did not have visitors, the information could not always be obtained."

People's conditions and care needs change. It is important that these are identified so that appropriate care can be provided. We saw that people's behavioural charts were used to monitor behaviour patterns before being referred to a specialist team for further assessment. In some cases, the local community mental health team were contacted to help care home staff care for people with changes in behaviour.

Q "We saw care plans had been reviewed monthly and changes to the person's care needs had been acted on and recorded. For example, we looked at the care records of a person who had become more aggressive and anxious... [and] had been referred to the old age psychiatry service. The service changed the person's medication to

ease their anxiety and reduce aggression. We saw that while this had worked, staff... were concerned the medication was making them too sleepy. Another referral was made and the medication was changed again..."

Where changes were not identified and managed, people's health and wellbeing was at risk.

Q "...there was a lack of systems in place to review changes in people's needs and behaviour on an ongoing basis, for example where a person's mobility needs had changed, which had resulted in increased falls. The risk assessment had not been reviewed in response."

4.1.2 Pain management

People living with dementia may not be able to tell staff about their pain and this can be overlooked, causing distress and unnecessary suffering. Pain can change how people behave. We saw a range of practices and approaches to identifying and managing pain. Some care homes and hospitals used a formal tool, such as pain assessment in advanced dementia (PAINAD) or the Abbey Pain Scale. Some staff, however, relied on observations of body language or facial expressions to help identify a person's pain. Good care was supported by identifying how an individual communicated they were in pain and also by consideration that a change in behaviour may be due to someone experiencing pain rather than their dementia.

Q "They told us [that] their relative was not able to tell staff verbally when they were in pain. They said, "He rubs his knees over and over again and all the staff know what it means."

Some care plans did not include information about how individuals communicated that they were in pain. Staff therefore relied on their own judgement, meaning that people were at risk of being in pain or receiving inconsistent pain relief.

Q "During our visit we observed that one person was holding their head and scrunching their eyes closed. When we spoke with this person they told us that they had a headache. A relative who was visiting told us, 'They give paracetamol if X says they have a headache, but I worry they don't check and X has to rely on asking...'. Although a member of staff had just completed the medication round in the lounge area, this person's pain had not been identified."

Q "Medical notes recorded a need for pain assessment... their daily summary recorded episodes of agitation and shouting out, but there did not appear to be any consideration that this may have been related to pain."

Our findings support the conclusions of *Pain in People with Dementia: A Silent Tragedy* (NAPP, January 2014) which looked at how pain is managed for people with dementia living in care homes.

4.2 Planning and delivery of care

4.2.1 Clinical guidelines, best practice

Guidance and resources are available for staff caring for people living with dementia. There is also a national commitment to addressing the challenges of supporting and caring for people living with dementia. In 2009, the Department of Health launched a national dementia strategy to support improvements in awareness, earlier diagnosis and intervention, and a higher quality of care. This was followed in March 2012 by the Prime Minister's challenge to help drive improvements in dementia care.

In June 2010, NICE published its Quality Standard (QS1) on dementia, describing what a high-quality dementia service should look like, and in April 2013 it published Quality Standard (QS30), which provides guidelines on supporting people to live well with dementia. In December 2013, NICE also published a Quality Standard (QS50) on the mental wellbeing of older people in care homes. Additional guidance and information is available from a range of sources including the Social Care Institute for Excellence,

the Alzheimer's Society, professional bodies and academic institutions.

We asked staff how they used the guidance to plan care for people living with dementia. In particular, we asked about awareness and use of the NICE quality standards on dementia. We saw examples of clinical guidelines being used effectively, but we found a lack of awareness or demonstrable use of best practice. In 40% of care homes and 33% of hospitals we visited, we found aspects of variable or poor care regarding staff knowledge and use of available guidance.

Q "As part of the provider's dementia strategy, they were using the Gemma Jones model of planning dementia care. This is a 'behavioural staging' model for meeting the needs of older people with dementia. A member of staff we spoke with was able to demonstrate how this model of dementia care benefited the individual. For example, we were told of the way people's behaviour needs were managed... that viewed the presenting behaviour in a positive way as opposed to a challenge.

Q "Staff were aware of these and knowledgeable about good practice in the care of people with dementia. The standards had been implemented through care planning, training and development of the environment.

Q "While the manager and staff were not aware of the standards for dementia care promoted by NICE, they used a wide range of guidance and training tools... In addition, we were shown documentation demonstrating the provider was working with the Dementia Services Development Centre, Stirling University, in developing a dementia strategy..."

4.2.2 Management of behaviour that challenges

Dementia can have a significant impact on people's behaviour, including feelings of confusion, anxiety and frustration. These feelings can result in people showing distress by shouting or screaming. When helping them to prevent or manage these feelings, it is important for staff to try to understand the cause so they can choose the most appropriate way to support the person. Information about a person's behaviour, and how staff should support people, needs to be shared when people move between services.

Where care was good, we saw examples of any changes in behaviours, or out-of-character behaviours, being noted and steps taken to identify the cause. This included ruling out physical causes such as infection, constipation or low blood sugar levels in the first instance. Where appropriate, we saw care homes asking for help from other professionals and support teams, such as the local dementia crisis team or the community mental health team.

Q "He can become very challenging at times. The staff are always very good with him and know what to say and do even when we don't."

We also saw times when not responding to changes in behaviour led to situations that could have been avoided, and how this adversely affected the person living with dementia and others around them.

Q "Later in the morning there was a verbal argument in a communal area. The two people involved were verbally aggressive to each other. A staff member arrived and gave a walking aid to one person involved in the argument, who left the room. There was no interaction about the argument and no reassurance was given to other people sat in the lounge. The verbal argument continued when the person walked back into the lounge 20 minutes later."

Detailed care plans helped staff to manage behaviours that challenge and support good care. They included information about the individual, what triggers the behaviour and strategies for managing it.

Q "Some people living at the home demonstrated episodes of challenging and distressed behaviour. There was no guidance in care plans about how to support

people... [and] no process for monitoring people's behaviours. This meant that there was no record to indicate whether people's behaviours were changing... [so] staff did not know when to seek appropriate professional advice...".

On some of our hospital inspections, staff called security to handle situations where people were exhibiting behaviour that challenges. This caused additional stress and anxiety to the person.

Q "In one person's record, for example, we read that they were 'very aggressive, distressed and confused'. There was no plan in place to ensure that staff had good knowledge about this person's condition and how it affected them... Staff we spoke with on one ward said that if 'physically aggressive' they could call security to come and help. We were told that this was a last resort because it could 'aggravate the situation.'"

4.2.3 Urinary tract infections

Urinary tract infections (UTIs) are an avoidable condition but are often the cause of hospital admissions. People with dementia who live in a care home are more likely to be admitted to hospital for potentially avoidable conditions, including UTIs.² Providing preventative care will help to avoid hospital admissions. There is also a risk of dehydration, which can lead to being admitted to hospital.

Good care included people at risk of developing UTIs being identified, and their care plans updated to include guidance about sufficient fluid intake and the importance of attention to personal care. In addition, staff continually prompting people to drink throughout the day and the use of urinalysis to check for infections supported good care and reduced the risk of UTIs.

2. Care Quality Commission. *The State of Health Care and Adult Social Care in England 2012/13*. November 2013.

Q "Senior staff had put together a checklist of common symptoms that care staff should routinely monitor. For example, the symptoms that a person may display if they had developed a urinary tract infection. This checklist gave an explanation of potential risks and the rationale for the close observations and actions to be taken. This helped to ensure that staff responded quickly to people's changing needs."

There were, however, examples where a risk of UTIs had been identified but was not supported with the appropriate care planning, delivery or

documentation. We received feedback from one carer who told us about their relative's stay in hospital:

Q "Mrs A was not prompted or helped to the loo at night and was left wet every night... This resulted in two urinary tract infections which cause additional confusion. Indeed, she was so confused by them that she could not hold a conversation with anyone, including me. Staff actually thought it was just her level of dementia and were amazed at how different she was when she finally got over the infection."

4.2.4 Falls

People living with dementia will fall more often than those living without dementia. And falls can lead to being admitted to hospital. The likelihood of dying following a hip fracture also increases for people living with dementia. It is important to make sure that care helps to reduce the risk of falling while supporting a person to remain as independent and mobile as possible.

We observed a number of measures in place to reduce the risk of falling, including appropriate use of bed rails, lowered beds, pressure alarm mats and increased staff supervision. Other examples of good care included providing exercise programmes and the use of a crash mat on the floor by the bed of someone likely to fall out of bed. Some care homes were also working with other health professionals to prevent falls. For example, one care home was working with a GP and a consultant gerontologist on a project to identify any medical triggers for falls.

In addition, several providers were monitoring, recording and investigating the causes of falls to identify any changes that could prevent them happening again.

Q "The manager gave specific examples of action taken following an analysis of incidents that had occurred at the home. For example, following a falls audit it was identified that the lighting in the foyer needed to be changed. Care plans had [also] been reviewed following falls to ensure that staff had clear guidance on the action to be taken to minimise this risk."

Q "...we observed large paper clocks in each area identifying the times that people had fallen. These were to remind staff to be vigilant at those times and monitor people to ensure they were safe."

However, there were occasions where action had not been taken to reduce the risk of falls. In one example, this had resulted in a potentially avoidable admission to hospital.

Q "...there had been no review of the falls risk assessment for a person after the first fall that resulted in a hospital admission. We found that this person then had a further fall that resulted in a hospital admission."

Environment is a significant factor in helping to prevent falls. See section 4.2.7 for our findings about environment.

4.2.5 Meaningful activity and occupation

Engagement in meaningful activities is important for good dementia care. It can help people to maintain a level of independence and functional ability, and improve people's quality of life. As with other aspects of caring for people living with dementia, understanding personal preferences and abilities will help to provide truly meaningful engagement and activities.

Examples of good care that we saw included:

Q "Staff took the time to have life-affirming conversations with people, and to offer small, individual activities, such as painting the person's nails and reading aloud to them."

Q "People with dementia were encouraged to participate, whether it was in communicating, doing tasks, or eating, in an effort to promote the maximum amount of independence."

Q "They let me do what I can, which is quite a lot, and I enjoy the company and everything that is provided for me."

As well as supporting people to be as independent as possible and engaging them in daily life, providing activities and opportunities to engage with the community supports the mental health and wellbeing of people living with dementia.

Q "There was an impressive activities programme in the home that was very much tailored to individual abilities and preferences. As well as activities, people engaged in normal tasks such as reading the paper and clearing the table after lunch."

Q "...some people enjoyed baking, singing and being involved in household tasks such as dusting and helping to set and clear the tables ... [one] person had been supported and encouraged to visit the local shops to collect their newspaper and shopping for other people until they were no longer well enough."

While not a home environment, it is important to consider how people living with dementia are kept occupied when they are in hospital, as it can help them to feel safe and calm. In one hospital they had developed distraction aids called 'twiddle muffs' that were designed to provide a simple stimulation activity for active hands. Some wards had board games and memory boxes, and there were also lounge areas for people to relax in. However, the extent to which hospitals had made all areas dementia-friendly environments varied. One person told us, "Generally very good care for dementia patients. Exceptional on Ward 40, and if other wards were as well supported the whole hospital would be excellent resource in dementia."

Q "We saw that the trust had made efforts to increase the profile of people with dementia and improve their care by encouraging involvement of non-medical staff, relatives and volunteers from the local community. They visited patients on wards during mealtimes to help people to eat their meals and have a 'chat'. Open visiting times

had also been introduced and this enabled more flexible and enhanced contact for people with dementia..."

However, some people living with dementia had few opportunities for social engagement or activities, which had an impact on their wellbeing.

Q "We spent time with one person in their room; we asked them if they had joined in any activities. We were told that there wasn't anything worth doing. They said they liked watching TV in their room but it was broken."

Q "Talking to people living at the home about activities comments ranged from 'I don't do anything I'm so bored' to 'I don't do any activities'. We spent time talking to the manager who told us that the staff did not have time to spend with people doing activities."

4.2.6 Privacy and dignity

Everybody has the right to be shown respect and treated with compassion. For people living with dementia this is particularly important in helping to recognise them as individuals, and acknowledging their difficulties in being able to express their wishes. Understanding the individual and recognising the behaviours that they may use to express their feelings is also important. Where staff had good knowledge of the people they cared for they were respectful and had built good relationships with them.

Q "During our observations we saw that staff were very responsive to people's needs and were able to recognise non-verbal signals which indicated that people required support. For example, we observed one person became a little agitated while sat in their chair [and] staff recognised this as a sign the person may need the toilet. They asked the person if this was the case and supported them appropriately."

Q "One relative told us, 'They don't talk down to him or give him platitudes; the atmosphere is calm, he likes that.'"

Q "A relative told us, 'The home provides a high standard of care in dementia. They treat everyone with respect and dignity. It isn't just good care they provide, it is loving care!'"

Q "Another relative said, 'When I visit, I watch how the staff treat other residents and they are always so caring. It reassures me for when I am not here!'"

Q "Staff were forthright when speaking to us about the importance of ensuring each person was treated with dignity and respect saying 'we speak to them as we would like to be spoken to' and 'we look after each individual, we value each person!'"

Q "We observed doctors speaking with patients living with dementia introducing themselves and telling the patient where they were and why they had been admitted. They explained the treatment they had received and the next plans. They checked the patients' understanding and gave them time to respond."

For people living with dementia, repeating actions or conversations and spending more time with them is often required to make sure that they have understood.

Q "We noted one member of staff had been tasked with assisting one person to eat their lunch. We saw the person was tired and not interested in eating at that time so the staff member left them to rest. They told us they would go back in a short while to see if they wanted to eat."

Respect for someone's dignity is not only demonstrated through behaviours, but also through the use of language and the care environment. We saw examples where language used was not respectful. A family member told us about their experience of disrespectful care for their relative.

Q "Lack of awareness around language used. Seeing behaviour as uncooperative rather than merely anxious and confused. Using term 'dirty' around incontinence to the resident. Patronising behaviour on occasion."

There were times when people were shown little respect or dignity. We were concerned to see differences in approach between people in the later stages of dementia and those with less complex needs living in the same home.

Q "One person, who was agitated and distressed in bed, was left with parts of their body exposed for lengthy periods of time. Their bed was facing a nurse's station and although staff did make several attempts to cover them, they did not do this consistently and the person was often left exposed in front of different healthcare professionals and visitors."

Q "Some rooms had little décor or pictures and no information to assist in getting to know the person. Other rooms, however, were warm and cosy and personalised. We found that the rooms with little or no personalised effects belonged to people in the later stages of dementia. This suggested that people with higher needs, or in the later stages of dementia, did not have their dignity maintained in the same way as people who were able to make choices and advocate their own needs."

Q "One person who stayed in their room was described by a member of staff as having 'closed down'. We found their room was the furthest away from the lounge and the person was not provided with any method of summoning help."

4.2.7 Environment

Environment can have a significant impact on someone living with dementia. It can cause anxiety and confusion, and make it difficult for people to orientate themselves. Financial support was made available in 2013/14 to a limited number of NHS and social care providers who were awarded funding through the Department of Health's capital funding project 'Improving the environment of care for people with dementia'. There is also information available from the King's Fund about how changes to the environment can improve the care of people with dementia.

We saw examples where care homes and hospitals had made improvements to the environment to support good care. These included the use of pictorial signage and photographs to identify bedrooms and bathrooms, and the use of lighting and colours to help people orientate. In one care home, bedroom doors had been brightly painted in different colours and one resident told us: "My room has got the blue door hasn't it?"

Ω "We found the décor of the home included colour differentiation. Lighting and carpeting were other areas that had been considered to support people's orientation and reduce the risk of falls. The en-suite facility in some people's bedrooms had light sensors which was beneficial at night, if the person needed to use the bathroom."

Ω "We noted the home had started to implement 'memory boxes' on each person's door. These contained pictures and items that might help the person identify their room."

Reminiscence areas helped to support people living with dementia. We saw examples of reminiscence lounges that were used for a variety of activities and the creation of street environments, including shops.

Ω "We saw that a sweet shop had been created in one unit which opened for short periods each day staffed by people using the service... The shop had been skilfully created as a reminiscence environment, as well as providing an opportunity for people to interact. We saw staff working with one person in the shop and they told us that the individual had previously worked in a shop locally during their working life. A reminiscence lounge was being completed on another unit at the time of our inspection that was to be used for tea parties and activity sessions."

In hospitals, some A&E departments had considered how confusing, noisy and disorientating the emergency department could be for patients living with dementia. One department had identified quieter, less busy areas away from the main activity of the emergency department. Another admitted people directly to the assessment unit, where possible, to avoid their spending time in A&E. There was variation in the extent to which wards had been made dementia-friendly. Some wards had a 'memory lane' and comfortable reminiscence areas, while others had special flooring or colours were used to distinguish the different areas of the ward. Hand rails and clear pictorial and written signage were also used.

4.3 Providers working together

4.3.1 Access to health and social care support

Caring for people living with dementia in a care home or in hospital involves support from a range of other professionals and services. For example, we saw care home staff working with GPs, community health teams, chiropodists and district nurses. Good working relationships existed with GPs, including care homes informing GPs of all new admissions and GPs visiting homes on a weekly basis. We also heard about weekly visits from community geriatricians and consultant psychiatrists, with some care homes holding six-weekly surgeries. In addition, care home staff sought advice and support from other professionals when a person's condition or behaviour changed.

“On the day of our visit, the senior partner GP at the medical centre used by people living at the home was undertaking a home visit... They told us staff were ‘very attentive’ to people’s needs... [and that] staff’s ‘threshold for contacting them’ was ‘appropriate’ with ‘no over or under reaction.’”

“The manager gave us a number of examples where someone has become more confused and staff had become concerned. They contacted the local GP when this occurred and several tests had been carried out in order to eliminate other causes of confusion, such as infections or constipation.”

There were, however, a few examples where providers had difficulty in accessing services, including the lack of a continence service in one area. Access to advice and resources for managing continence is an important part of supporting good care.

As well as support from health professionals, there were examples of care homes engaging with other organisations in the voluntary and community sector.

“Every six weeks staff supported people... to go to a local centre which helped people with dementia with their social needs.”

“...the service worked in partnership with a large supermarket chain... The supermarket supported the service with the provision of goods to help [create a dementia-friendly] environment... and to support people with activities. For example, the supermarket donated a large Christmas tree... over the Christmas period...”

The importance of professionals and other agencies working together to make sure that discharges from hospitals were well managed was highlighted on our inspections. Many hospitals had dedicated discharge teams and started to plan for discharge from the time of admission, ensuring that the individual's needs were met.

4.3.2 Sharing information between care homes and hospitals

Admission to hospital can be stressful and unsettling for people living with dementia. We looked at what care homes and hospitals were doing to minimise the anxiety caused, and in particular at how information was shared between providers.

We found aspects of variable or poor care with the arrangements for sharing information in 27% of the care homes and 22% of the hospitals we visited.

There was a wide variety of documents used by care homes. The most effective of these included details of medical history, current medication, a profile of psychological and emotional needs of a person, their preferences and communication needs. Some care homes used the Alzheimer's Society 'This is Me' document, while others used documents called 'hospital passports', which included information such as 'how you know that I am in pain' and 'things I don't like'. Sharing information about how a person's behaviour is affected by their dementia is an important part of minimising the anxiety when they move between providers.

Some care home staff accompanied people to the hospital to provide additional support. This was appreciated by the people we spoke to, their families and staff. Families and relatives told us that they valued being kept informed about any admissions to hospital from the care home.

Q "One of the staff from here went with me and stayed with me until I was on the ward. They told us this had made them feel less worried."

Q "A relative we spoke with told us, 'We were happy with the hospital admission and we were kept well informed about it all. Couldn't fault it; they were well looked after in hospital too.'"

However, these documents were only useful if completed fully, kept up to date and shared with the relevant staff. We saw examples where the documentation was not being used effectively. Some information that was sent to the hospital only focused on medication or physical health needs. On one occasion, staff were unable to access the documentation for a night time emergency admission because it was locked in the manager's office.

 "For one of the three people who visited the accident and emergency department during the night, and was subsequently admitted for treatment, we found that no information had been supplied to the hospital at that time. As a result, the hospital phoned the home to obtain information about the person. This was confirmed by a member of staff that we spoke with. They told us, 'I was on duty at night when X (referring to person who lives at the home) went to hospital. The paramedics came promptly but the office was locked - they wanted a photocopy of X's care plan to take with them and I couldn't provide it. All I could do was give them X's medication and next-of-kin details and packed a few personal belongings. At 6.15am we had a call from the doctor asking for more information about X's sleeping, mobility, eating, drinking and generally what X is like'. We discussed this with the manager who confirmed that at night the office was locked and staff had no access to... records or the photocopier machine."

 "We saw one patient had two completed booklets; one completed by the care home they were living in and one by the hospital. The information in these booklets was not the same and could lead to some confusion amongst staff delivering care to the patient."

In other cases, we found that the information provided by care homes was not adequate. We saw an example of one patient who had been admitted to A&E with a pre-admission assessment which was over a year old. This indicated the patient had a range of needs that would need to be addressed, such as pressure ulcers, poor mobility, and behaviour that was changeable. In this instance the doctors had to contact the care home to check whether the information was still accurate and up to date.

Staff from both care homes and hospitals told us about the impact of not receiving information. This included times when information they provided had not reached the relevant people, or where information received was not sufficiently detailed and required a follow-up by telephone. This often resulted in delays as it could be difficult contacting the relevant people. One member of staff told us: "They always ring up and ask us to tell them about the person; the documents seem to go astray."

Q "Junior doctors we spoke with told us that where patients had additional information, like a healthcare passport, 'this is brilliant, really helpful'. They explained they did not always receive information about patients admitted from care homes [and] always made contact with care home staff to gather additional information about the patient, but that [at] night this was sometimes difficult as care home night staff did not always have the information the doctors required... this left them with a dilemma about whether it was appropriate to contact the patient's families for further information, particularly in the early hours."

Q "Staff told us that despite sending extensive documentation and a member of staff with residents to hospital, they would get frequent phone calls from the hospital to check people's needs... this could happen several times if the resident moved wards within the hospital."

Q "Although she felt hospital nursing staff usually gave good verbal feedback about a person's stay in hospital - just before transfer back to the home - the written information received was 'often very patchy' and sometimes didn't arrive at the home at all."

We saw examples of when shared information had not been acted on. In one care home, the hospital discharge information provided advice for staff on monitoring for signs of a blood clot, but this information was not included in the care plan.

4.4 Staffing

Staff have an important role in supporting people living with dementia to have a good quality of life. Having the right knowledge, skills and time is essential to good care. Key to achieving this is ensuring that there is the right number of staff, with the right values, who are supported through training, supervision and access to resources.

4.4.1 Lead roles

We saw staff with lead roles in dementia care in some care homes and hospitals. Their role was to improve the quality of dementia care and support to colleagues caring for people living with dementia. The definition of these roles and how they were supported varied. The extent to which these roles improved the quality of care was not always clear, but they did support good care for people living with dementia.

Dementia champions were used effectively on some wards but not on others. A nurse on one ward told us: "It is good to know that someone has the knowledge and the skills to lead on this important subject."

We saw examples in care homes where people were allocated a key worker, but the effectiveness of this role varied. Although the key worker role worked well in some homes, there was confusion about it in others. Staff at one care home told us that the decision about who they supported was made on a daily basis and therefore provided no continuity of care. However, people and their carers told us they valued having a named person they could contact.

Q "We all have a key worker. We talk to them. If they can't sort it out, they would pass on to someone else."

Q "They look after me, they really do. I do have one special carer that I can talk to if I have any problems, laugh and cry with. She is a diamond. The other day I had such an itchy back but she soon sorted it for me."

Q "Mum now has an appointed carer who liaises with all the carers who were on duty, her care plan is clearly updated [and] we have a 'go to' person. There are lots of activities and the home is run as a 'family', the carers are her family and mum's wellbeing and dignity is maintained. She is nurtured."

4.4.2 Training and support

There was a range of training courses for staff caring for people living with dementia. Not all staff had received training, and where they had it this did not always improve care. We saw examples where some information about dementia formed part of the induction programme but was not followed up with more training,

education or development opportunities. The most effective training involved a practical element and included time for staff to reflect. However, providers did not routinely monitor whether training improved the quality of care for people living with dementia.

Q "We saw care staff displayed caring, compassionate qualities, and they demonstrated that they understood how to respond to needs and often frustrations of a person with dementia. All newly employed staff participated in the programme which simulated the effects of ageing and went through a range of activities designed to simulate the impact of dementia. Members of staff told us this made them appreciate the challenges many of the people with dementia face and recognised the importance of their role as care workers."

Q "Staff we spoke with told us that the management team was very supportive... [and ensured] that all members of the team were offered regular supervision, and an opportunity to discuss any problems or concerns over practice or their own professional development."

Q "The three staff we spoke with told us they liked working at the home... [but] told us they were not trained in dementia care."

Q "Staff commented: 'We care about the residents but it's difficult at times.' They also said: 'I need to have updated dementia training so I can respond more effectively and inform other staff!'"

4.4.3 Numbers of staff

The time staff had to spend with people, over and above providing the required aspects of personal and clinical care, varied across the care homes and hospitals visited. However, it was often a significant factor in caring for people living with dementia. We spoke to several managers and staff who expressed frustration that, due to a lack of resources, they were not able to provide the care needed.

Q "We saw that staff knew people well and understood their needs. All the staff we observed had developed a good rapport with people, however, very little quality time was spent with each person as staff were so busy... A member of care staff told us, 'I really do care about the people living here, [but] we are just always too busy to spend quality time with them!'"

Q "My mother, who has dementia, has only been here a short time but in the last few weeks she has been happy, stress-free and well looked-after. The staff have loads of time to spend with residents and while visiting I have never experienced them being hurried or ignored. Lovely people."

We saw how people living with dementia were affected when there was not enough staff, including changes to their behaviour that caused distress to them and others around them.

Q "During the morning we spent observing the wellbeing of people in the downstairs lounge areas, we saw that one person called for help seven times in an 18-minute period. There was no member of staff available... [and] no... bell available to call for assistance. We saw that other people were getting angry with this person calling out, with one person telling them to shut up. We observed that for a 20-minute period there were no members of staff in the lounge. This meant that the wellbeing of people was not being monitored and when they required assistance it was not available. This was evident when we saw one person becoming agitated with another person living at the home. This resulted in verbal and physical aggression with the people kicking and hitting each other."

Q "We found that people with dementia did not always receive care which met their needs. For example, during our visit we observed one person being left alone on the commode for an hour. This person was calling for assistance during this time, but staff did not respond to the person. When we alerted staff, they told us, 'They always call out and would be calling out if they were not sat on the commode.'"

4.5 Involvement

People living with dementia may need support in making decisions about their care, including decisions about their daily lives, because they may not be able to communicate or understand the information provided. It is essential that everyone is recognised as an individual, requiring different levels of support. Families and carers often have the best understanding of a person and how their dementia affects them. In 33% of care homes and 61% of hospitals, we found aspects of variable or poor care regarding how people, together with their families and carers, were being included in decisions about their care and choices about how to spend their time.

4.5.1 Choices and decisions about care

When care was good people were supported to make choices about their daily routines and care. One person told us: "I am able to tell staff when I would like to go to bed and get up, or when I want a bath; they are very good to me." Another told us: "A nurse came to see me today about my mouth problem. We agreed what to do together."

Pictures and regularly repeating information were used to help people living with dementia to make decisions. For example, we saw people being shown options of plated meals to help them make a choice about their meal.

Some providers used leaflets to give information to people living with dementia, their family and friends. In one hospital, this included a contact number, general overview about dementia and a description of the trust's 'Forget me not' scheme. It also included tips for carers and details about where to go for advice and support on returning home. Other examples included information boards that provided details about meals, planned activities and events.

Over time, people living with dementia may lose the ability to make some decisions. While they may not be able to make complex decisions, they may still be able to make decisions about daily life. The Mental Capacity Act (MCA) 2005 is designed to support people to make decisions

for themselves. Although we saw the MCA being used appropriately, we also found that people's freedom to make decisions for themselves was restricted without proper consideration. This supports previous research that highlighted there is a widespread lack of understanding about the Act.³

Q "We found that individuals' capacity to make decisions was assessed... For example, we saw that a person's capacity to make a decision about being admitted into the care home had been assessed. Where people... [did not have the] capacity to make an informed decision, meetings had been held with family and other agencies to decide what action was in the person's best interests. We also that saw people had support to make decisions. For example, one person had made a decision not to have a surgical procedure, and advocacy services had been used to support them in this process."

3. Care Quality Commission. *Monitoring the use of the Mental Capacity Act Deprivation of Liberty Safeguards in 2011/12*. March 2013.

Q "We found that decisions had been made which restricted a person's choices. For example, one person wished to access the garden. However, the door to the garden was locked. We alerted a member of staff who told us this door was kept locked to keep people safe. They told us when they had time they would go in the garden with people. We found that there was no evidence [that] this had been discussed with the person. There was no detail or risk assessment in their care plan. People who wanted to access the garden were not assessed or consulted to determine their safety to do so. This meant that people's access to the outdoors could be unnecessarily restricted."

While some people may not be able to make complex decisions, they may be able to make decisions about daily life and we saw examples of staff asking people how they wanted to spend their time and seeking consent to undertake personal care tasks.

4.5.2 Involvement of family, friends and carers

Family and carers play an important role in working with care providers. They often knew the person best and how their dementia affected them; they were able to provide staff with useful information. There were good examples of care where family members were involved as equals in supporting a person's care. One member of staff explained: "It's important to remember that relatives know people better than anyone. Before anyone comes here, time is spent in making plans together...".

Relatives in one care home told us that they were not involved in developing care plans and they did not feel that these accurately reflected their family member's life history, social or family preferences. In addition, care plans were not up to date and did not provide enough information. As a result, people were sometimes distressed and this was not managed by staff.

Q "We can ring any time to find out any information about what's going on and we feel well informed... if I've not been in touch for a couple of weeks they'll ring me to update me on their care."

We saw examples of advocacy services being used successfully where people needed support but did not have family members to support them. At one care home an advocate told us that he supported people to make sure their choices were understood and respected at the home, and also at statutory reviews with social services.

A local Healthwatch organisation shared this story with us, which demonstrates the important role of advocates:

Q "An older woman receiving end-of-life continuing care in a care home, with dementia and various serious physical health needs, had no hearing aid, due to it being lost in transit between care homes and hospital. Her lower denture had also been lost and staff at the care home seemed not to recognise the

importance of improving the quality of her life by ensuring that she had them. An advocate was able to help her get them and fight for her dignity and fundamental right to communicate. Though the woman lacked capacity, the advocate pursued the woman's rights and as a result her health improved to the extent that consideration was given to reducing the level of care that she required from 'end of life' to 'general nursing'."

4.5.3 Diversity and inclusion

We held four focus groups facilitated by the Race Equality Foundation. Participants included people living with dementia, carers of people living with dementia and staff from community dementia organisations. Chinese, South Asian, Pakistani and Black Afro-Caribbean communities were all represented. Not recognising dementia as a health condition was a key issue in some communities, which in turn meant people were often reluctant to access services. Language was also a barrier to people accessing information and services, and an area of anxiety for people

considering residential care. People described how they valued the support from community and voluntary services.

The discussions at these groups were broader than the focus of this inspection programme and provided a useful opportunity to understand how we can strengthen our engagement with Black and minority ethnic groups. This will help our inspection teams to improve our understanding of people's experiences of dementia care.

4.6 Monitoring the quality of care

4.6.1 Culture and leadership

Improving the quality of dementia care is more than putting in processes and training programmes. It can require changes to culture, driven by strong, committed, leadership, together with opportunities to take time for reflection on practice. We met managers of care homes and wards who were passionate about providing good quality care. Some of these were very knowledgeable about caring for people

living with dementia and created a culture where good care was the norm. Part of this culture was monitoring the quality of care provided, using feedback and learning from incidents to make improvements. This also extended to evaluating the impact that initiatives (including training for staff or the use of dementia schemes) were having on the quality of care.

Information we received from an overview and scrutiny committee confirmed the value of strong leadership, “Where there was strong, quality leadership in place with high expectations from staff that care and dignity were paramount, a better service was provided.”

 "The manager was well experienced and qualified in managing services for people with dementia and had achieved a degree in dementia studies from Bradford University. She told us she cascaded

her knowledge and, at times, delivered training to the staff team. She constantly looked to improve practice and took part in dementia care initiatives. For example, having a ‘dementia champion’ who acted as a role model, and registering with the ‘dementia friends’ initiative to help people with dementia in their daily lives and inclusion in their local community.”

4.6.2 Monitoring quality and making improvements

We did see some care homes and hospitals using aspects of national dementia initiatives to inform the care they provided. This included schemes to help staff identify people living with dementia and who may need additional support, such as the ‘Forget me not’ scheme. The dementia friend initiative was also being introduced into some care homes and hospitals. However, arrangements to monitor the quality of care provided (including the use of feedback and learning to improve) were not always robust or did not always provide sufficient focus on dementia care.

Most of the hospitals we visited had a dementia strategy in place, often supported by a dementia steering group which monitored the progress of new initiatives, such as dementia-friendly environments and rates of diagnosis. This information was reported to trust boards and provided a focus on care improvement.

As described in section 4.2.1, there is variability in the awareness and use of best practice guidelines, including NICE quality standards. This variability extends to how providers used guidelines to monitor the quality of care. In 37% of care homes and 28% of hospitals we visited, we found aspects of variable or poor practice in arrangements for monitoring the quality of dementia care.

A dementia care mapping tool was used by some providers. This is an observational tool that assesses the wellbeing of an individual and helps staff to understand how best to support them. For example, by using the tool, one care home had identified that one resident preferred to walk around rather than sit at a table for their meals. So the care home made finger food for this person to support their preference. This tool also helps staff to reflect on their practice.

Q "There were effective systems for monitoring and improving the care for people with dementia. The manager showed us a range of tools that they used to audit the quality of the service, which included checking staff practice following training courses. The Alzheimer's Society 'Inspiring action' checklist was used and the service had an audit tool for a 'Quality check for dementia care'. We saw that areas for improvement had been identified from recent audits, which included the need for improved signage around the service and contrasting colours in the décor, including red toilet seats to help people with dementia see things more clearly.

"The manager issued staff with a weekly update newsletter. This included updates to practice from organisations such as the Social Care Institute for Excellence (SCIE). The manager had encouraged staff to sign up for SCIE newsletters."

People living with dementia are more at risk of falls, UTIs and malnutrition. Recording when these happen and investigating the causes can prevent them recurring or stop them happening in the first place. Ensuring an environment is dementia-friendly helps keep people safe, and can help prevent hospital admissions and long stays in hospital. One carer told us: "Input by a specialist nurse from the local NHS hospital trust has led to a 30% reduction in admissions to hospital over the previous three months."

Q "The service used a computer software package for health assessments. This meant if the person appeared unwell, the information relating to the person would be entered on the system. The system would then inform staff if they needed to refer to the person's GP or use emergency services. Staff told us they had found this a very effective tool as it had reduced the number of GP call-outs, and data showed there had been a reduction in hospital admissions... They also told us [that] when they wanted a GP to come to the home, they would fax the information to the GP so the GP could see the rationale behind the call."

Q "Over the previous six months, the frequency of falls, accidents, UTIs and malnutrition was low. The manager stated that this was due to ensuring care records were reviewed on a monthly basis, which then resulted in early, safe and effective interactions."

We saw care homes and hospitals using questionnaires, meetings and comment boxes to gain feedback. The best examples made sure that they were accessible to people living with dementia, for instance by using pictorial versions, or staff helping people to complete a questionnaire or recording their responses for them. We saw an example of a hospital that used patient stories as part of their open board meetings and saw that this had recently included the story of a patient living with dementia.

Families and relatives were asked for feedback to support people who had difficulties in communicating. We saw examples of good practice where the views of the person living with dementia took precedence, and where advocates were used to help people who did not have any relatives to represent their views.

Q "The manager explained that regular surveys of people's and relatives' views of the service were carried out. A specific format of the survey had been developed to make it possible for people with dementia to share their views. This used an easy-read and pictorial format with a large font to make it more accessible for people with dementia."

Q "Records showed [that] each person with dementia or their relative was asked to complete a 'residents' pre-meeting questionnaire' every month. Questions included: 'Are you happy living here?'; 'do you feel your needs are met?'; 'would you like to do/see more activities?'; and 'do you feel you have sufficient opportunity to tell us what you think and how you feel?'. Information from this questionnaire was used at the residents' meeting or on a one-to-one basis for discussion about how the home could continue to improve the way in which it met people's needs. We saw records confirming people who lived at the home were asked for their input before a new member of staff had completed their probationary period and their employment confirmed. Amongst other things, people were asked how well the staff member had spoken to them, responded to them and respected their dignity."

5. OTHER FEEDBACK

In addition to our inspections, we asked people living with dementia and their families to tell us about their experiences of care. They told us being treated with care and compassion by staff who understood their needs was the most important thing for people and their relatives. They also wanted the best possible quality of care.



When asked about what contributed to a poor experience of care they told us:

Q "Nobody asking or listening to what I say. People treating me like I cannot think at all anymore. Feeling so disempowered that I feel like nothing."

Q "The professionals we encountered had very little knowledge on dementia, and of my mother's needs. At times we were made to feel that she was invisible, being old and suffering with Alzheimer's was life and what did we expect them to do. We had to ask for pain relief for her but kept waiting hours for this due to the prescribing doctor being busy elsewhere. Also mum being asked about drinks or given drinks but staff having no knowledge of mum's non-existent communication skills."

They also highlighted the negative impact a hospital stay could have on a person with dementia.

Q "Moving from the hospital into a more homely environment helped her to feel less frightened. Having more room to have her own things around her and less restriction on visiting times made the experience easier for all involved."

Q "Arriving at a home where dementia was understood and being able to expunge as quickly as possible all mum's memories of hospital."

When asked what could have made the experience better, they told us:

Q "Training in dementia. The need for everyone working in a care situation to be aware how to deliver care and realise [that] it's not always how it's written on paper. At the time of my mum's admission to hospital, the ward manager actually said he could have done with my sister and myself there to train his staff. People with dementia may not seem to be aware of their surroundings but I feel they are aware but [they] are unable to express that..."

Q "Time to explore my options. An advocate who could voice out for me or support me to voice out for myself. Listen to me and take the time to communicate to me."

Q "More time with the person living with dementia and not to make them feel rushed into making any decisions."

Q "I think just simple care, manners and respect from everyone involved is needed. Doctors need reminding that most of the time the person involved has been a pillar of the family and feelings naturally run high."

Other feedback focused on support for diagnosis and for people living at home. People highlighted that more support is needed to prevent people living with dementia moving into care homes or spending time in hospital.

6. CONCLUSIONS AND NEXT STEPS

It is widely acknowledged that there are an increasing number of people living with dementia living in care homes and receiving care in hospitals, and that people living with dementia have specific care needs.

However, the quality of dementia care is variable across providers, and transitions between services need to be improved. At present, a person living with dementia is likely to experience poor care at some point along their care pathway. People living with dementia have the right to expect they will receive good care and the variability in the quality of care they experience is unacceptable.

Comprehensive assessments that support personalised care – delivered by knowledgeable, skilled staff who have the time to care and in an appropriate environment – are critical to achieving good dementia care. Other factors include sharing information between providers, managing risks and monitoring and improving the quality of care.

Good and outstanding dementia care requires all of the above factors to be effective. Managers in care homes and hospitals also need to create a culture and ethos of good care.

While this review has focused on care homes and acute hospitals, ensuring good quality care for people is the responsibility of many, including other health and social providers, commissioners and regulators. It is essential that organisations and stakeholders work together to support people with dementia to live well – and the findings in this report are relevant to all.

Actions CQC will take

We are committed to taking action to hold services to account in our inspection and regulation of providers to ensure that high quality care is provided for every person living with dementia.

To support us in doing this effectively we will:

- Appoint a new national specialist adviser for dementia care.
- Train inspectors across all inspecting teams to understand what good dementia care looks like so that their judgements of the performance of providers are consistent and robust.
- Include a separate section in hospital inspection reports that shows how well the hospital cares for people living with dementia.

7. REFERENCES

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- National Institute for Health and Care Excellence (NICE). *Quality Standard 50: Mental wellbeing of older people in care homes*. December 2013.
- Napp Pharmaceuticals. *Pain in People with Dementia: A Silent Tragedy*. January 2014.

APPENDICES

Appendix 1: Methodology

Sample selection

Using data from our 2012/13 thematic review, we identified a sample of 129 care homes and 20 hospitals, from 22 local authority areas.⁴ This data provided information about people with dementia, including how often they were admitted to hospital with a potentially avoidable condition and how long they stayed in hospital when compared with people without dementia. We selected care homes and hospitals and local authority areas that were outliers in respect of the data. Within each local authority area we selected care homes that were likely to admit people to the identified hospital. When finalising

the sample, we also considered care homes and hospitals that were due an inspection as part of our annual programme. We also inspected a care home where we had serious concerns about the quality of care being provided for people with dementia, and a hospital being inspected using our new regulatory model.

4. Care Quality Commission. *The State Of Health Care and Adult Social Care in England 2012/13. Technical Annex 3: Dementia thematic review 2012/13*. November 2013.

The inspections

Our inspections looked at three main areas: how care was planned and delivered; how providers worked together; and how quality of care was monitored. For each of these areas we looked at specific aspects of care, and these were used to structure the reports of our findings. For some inspections, we combined the dementia themed inspection with a planned inspection, or followed it up with another inspection to look at other aspects of care.

We used the Short Observational Framework for Inspection (SOFI) tool to observe people's care

and help us understand the experience of people who could not talk to us. This tool is particularly useful when looking at care for people with dementia or communication difficulties.

All inspections undertaken as part of this themed inspection programme were unannounced. A comment box was left with the service for a week after the inspection to allow people not present on the day, such as families, staff and other health professionals, to provide feedback on the quality of dementia care.

Inspection teams

Experts by Experience (people who have experience of using or caring for someone who uses this type of service) and specialist advisors were part of our inspection teams. The specialist advisors all had professional experience of dementia care and included specialist dementia nurses, doctors and managers of dementia services. Each inspection was led by a CQC inspector, with 96% of inspections supported by an Expert by Experience and 38% supported by a specialist advisor.

	Care homes	Hospitals	Total
Expert by Experience	123 (95%)	20 (100%)	143 (96%)
Specialist advisor	39 (30%)	18 (90%)	57 (38%)

Involving people and requesting feedback

We worked with a range of voluntary and community organisations to gather feedback from people with dementia and their families. They were also involved in shaping the inspections and contributing to the review findings.

We received feedback from other stakeholders including local Healthwatch organisations, overview and scrutiny committees, networks of dementia groups, and networks of older people and carers organisations, for example Age UK and Carers UK. We also worked with the National LGBT Partnership and Race Equality Foundation to hear from Black and minority ethnic and Lesbian, Gay, Bisexual and Transgender (LGBT) communities, as there is evidence to suggest

that these communities particularly experience challenges in accessing and receiving good dementia care.

The Race Equality Foundation and Age UK facilitated a number of focus groups, and Regional Voices conducted a survey of people with dementia, their families and carers.

To increase the feedback received, we also set up a dedicated email address and made a questionnaire available on our website. These ran for three months during the inspections. Feedback was then used to inform the findings of this report. When a provider was named in feedback, this was shared with the regional inspection team for review and follow up as appropriate.

Appendix 2: Further reading

Dementia Action Alliance.

The Dementia Care and Support Compact

www.dementiaaction.org.uk/dementiacompact

Department of Health.

Prime Minister's challenge on dementia

www.gov.uk/government/publications/prime-ministers-challenge-on-dementia

Donaghy I. *Dear Dementia. The laughter and the tears.* Hawker Publications, London 2014

National Institute for Health and Care Excellence (NICE).

Tailored resource on supporting people to live well with dementia

www.nice.org.uk/Guidance/QS30/Resources

National Institute for Health and Care Excellence (NICE).

Support for commissioners of dementia care

www.nice.org.uk/resource/QS30/html/p/cm48-nice-support-for-commissioners-of-dementia-care?id=r2oykm5h4p764o7ihnvghrp574

National Institute for Health and Care Excellence (NICE).

Tailored resource on mental wellbeing of older people in care homes

www.nice.org.uk/Guidance/QS50/Resources

Royal College of Nursing.

Dementia

www.rcn.org.uk/development/practice/dementia

Royal College of Nursing and Carers Trust.

The Triangle of Care. Carers: A Guide to Best Practice for dementia care. Carers Trust 2013

www.rcn.org.uk/development/practice/dementia/triangle_of_care

Skills for Care.

Dementia

www.skillsforcare.org.uk/Skills/Dementia/Dementia.aspx

Skills for Health.

Dementia

www.skillsforhealth.org.uk/service-area/dementia/

Social Care Institute for Excellence.

Dementia Gateway

www.scie.org.uk/publications/dementia/index.asp

Dementia Services Development Centre, University of Stirling

www.dementia.stir.ac.uk/

Bradford Dementia Group, University of Bradford

www.bradford.ac.uk/health/career-areas/bradford-dementia-group/

Association for Dementia Studies, University of Worcester

www.worcester.ac.uk/discover/association-for-dementia-studies.html

Enhancing the Healing Environment, Kings Fund

www.kingsfund.org.uk/projects/enhancing-healing-environment

Royal College of Psychiatrists, National Audit of Dementia

www.rcpsych.ac.uk/workinpsychiatry/qualityimprovement/nationalclinicalaudits/dementia/nationalauditofdementia.aspx

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Advisory group members:

Gill Ayling Department of Health

Frances Blunden Foundation Trust Network

Jim Byrom Registered Nursing Home Association

James Cross Skills for Care

Trish Davies Relatives and Residents Association

Anne-Marie Dean Healthwatch Havering

Yvonne Franks NHS England

Mariela Gaete-Reyes Bournemouth University
Dementia Institute

Martin Green Independent sector
dementia champion

Geraldine Green Alzheimer's Society

Chloe Hood Royal College of Psychiatrists

Farah Islam-Barrett Race Equality Foundation

Ann Johnson Individual living with dementia

Victoria Jones Expert by Experience

Pat Jones-Greenhalgh Association of Directors
of Adult Social Services

Joanna Lenham Social Care Institute
for Excellence

Andrew Lovegrove Skills for Health

Stephen Lowe Age UK

Simon Marrow Healthcare Quality Improvement
Partnership

Bren McInerney Community Member and
Co-Chair of the CQC eQuality Voices group

Katherine Murphy Patients Association

Barbara Pointon Former family carer;
Ambassador for the Alzheimer's Society and
Dementia UK

Chris Quince Alzheimer's Society

Jill Rasmussen Royal College of
General Practitioners

Christine Redfern Support for Ann Johnson

Cliff Reynolds Healthwatch Havering

Kim Rutter Social Care Institute for Excellence

David Sallah Health Education England

James Stephens Skills for Health

Deborah Sturdy Independent Consultant

Rachel Thompson Royal College of Nursing

Ian Turner Registered Nursing Home Association

James Warner Royal College of Psychiatrists

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How to contact us

Call us on > 03000 616161

Email us at > enquiries@cqc.org.uk

Look at our website > www.cqc.org.uk

Write to us at >

Care Quality Commission

Citygate

Gallowgate

NE1 4PA



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