

CRACKS IN THE PATHWAY SUMMARY

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

OCTOBER 2014



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

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.

Overall 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



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."

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.

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."

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.

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.



> Planning and delivery of care

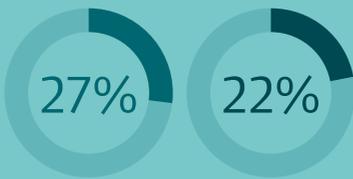
In 34% of care homes and 42% of hospitals we found aspects of variable or poor care regarding how the care met people's physical and mental health and emotional and social needs.



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.

> 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.



Care home

Hospital

> 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.

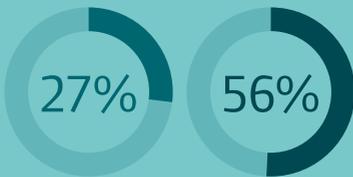


Care home

Hospital

> 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.

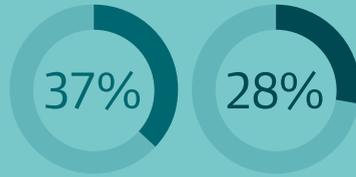


Care home

Hospital

> 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.



Care home

Hospital

Q "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 pages 8 and 9).

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.

 "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.

 "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.



"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.

 "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 of 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

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