Fix Dementia Care Hospitals

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Fix Dementia Care: Hospitals marks the start of a new Alzheimer’s Society campaign looking at the experiences of people affected by dementia in a range of health and care settings. It contains the results of Freedom of Information requests from hospital trusts across England, a self-selecting sample of carers of people affected by dementia who completed a survey on Alzheimer’s Society’s Facebook page and analysis of government and NHS data. It also includes the stories of four families affected by dementia who have had experience of dementia care in hospitals.

It sets out recommendations for the NHS and health regulators to improve the experiences of people affected by dementia in hospitals and Alzheimer’s Society will be campaigning to ensure they are implemented.

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Foreword

Poor care in hospital can have devastating, life-changing consequences for someone with dementia. Becoming malnourished because you cannot communicate to hospital staff that you are not eating enough, or falling and breaking a hip because you weren’t helped to the toilet can mean the difference between being well enough to return to your own home or being discharged to a residential home.

We place great trust in the NHS to take good care of us when we’re unwell and there are many examples of excellent care across the country – some of which we showcase in this report – but our investigation into hospital care in England for people with dementia reveals a less comforting picture. It is one that has been obscured from the public by layers of bureaucracy, bad governance and weak regulation.

Through Freedom of Information requests to hospitals and first-hand testimony collected from people with dementia, their families and carers, we have discovered evidence of the variable care that people with dementia face – in some cases shockingly poor – and the hundreds of millions of pounds of public money wasted delivering it.

The standards of care differ so much around the country that people are gambling with their health and wellbeing every time they are admitted to hospital. At the moment, there’s no way for patients or their relatives to find out in advance what kind of care they’re going to get. This has to change.

Lasting change will not be achieved through easy or quick solutions so our recommendations are pragmatic to start us on a journey of transformation. We’re calling on all hospital boards to publish an annual statement on the quality of dementia care in their hospitals, and on Care Quality Commission and Monitor to make the quality of dementia care a priority in their regulation of hospitals.
Putting this information in the public domain will finally put an end to a culture in which it is easier to find out about your local hospital’s finances than the quality of care you’ll receive if you have dementia. It will allow us to stand together to collectively hold hospitals to account, ensuring the continued improvement of hospital care for people with dementia and better use of NHS budgets.

This report marks the start of Alzheimer’s Society’s new Fix Dementia Care campaign. During 2016 we will be examining the quality of dementia care in hospitals, care homes and care at home, addressing the issues that arise with ways to change policy and practice to ensure everyone gets the care they need, whatever the setting.

Jeremy Hughes CBE
Chief Executive
Summary

The Francis Inquiry into the Mid Staffordshire NHS Foundation Trust (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) reported the need for accountable leadership and good governance to ensure good quality care in hospitals. The National audit of dementia care in general hospitals (Royal College of Psychiatrists, 2013) built on the Inquiry’s findings, recommending that hospitals should have a dementia strategy outlining their plans to improve dementia care, a dementia champion on the board and a defined process for the board to review the quality of dementia care. There should be a clear, personalised dementia care pathway from admission to discharge with an identified senior clinician to oversee its implementation. All staff should be dementia aware; those delivering care should receive dementia training appropriate to their role and the hospital environment should be adapted to be dementia friendly.

The Dementia Action Alliance (DAA), supported by Alzheimer’s Society, has led important work to develop good practice in line with these reports by securing hospitals’ commitment to deliver the personalised dementia care outlined in the Dementia friendly hospital charter (Dementia Action Alliance, 2014) and National dementia declaration (Dementia Action Alliance, 2010). We commend the hospitals involved in this work but more needs to be done to improve practice. Our report has found that poor dementia care is still widespread, that the quality of care varies widely between hospitals and that millions of pounds are being wasted on substandard care.

We found that:

- only 2 per cent of those we surveyed felt that all hospital staff understood the specific needs of people with dementia
- thousands of people with dementia are being discharged between the hours of 11pm and 6am each year
- in the worst-performing hospitals, 52.2 to 70.6 per cent of people aged over 65 who had a fall in hospital were people with dementia
- people with dementia stay five to seven times longer than other patients over the age of 65 in the worst-performing hospitals
- £264.2 million was wasted due to poor dementia care in hospitals in 2013/14.

To truly fix dementia care in all hospitals will take time. The following recommendations are intended to accelerate that transformation and complement those from the Francis Inquiry and National Dementia Audit. They must be built into the forthcoming implementation plan for the Prime Minister’s challenge on dementia 2020 (Department of Health, 2015) to ensure unified, system-wide change. Fundamental to our calls is the idea that, by making hospitals more transparent, they become more accountable and this motivates improvement.
Regulators need to do more to support this by improving the way they target inspections of dementia care in hospital and enforcing change where needed so that no one has to experience poor quality care.

Alzheimer’s Society calls for the following three recommendations. See section 8, ‘Recommendations’, for further details on these:

1. All hospitals to publish an annual statement of dementia care

   This should include:
   - satisfaction levels among patients with dementia and their carers
   - figures showing the number of falls
   - the number of inappropriate discharges, including those between 11pm and 6am, with less than 24 hours’ notice or with significant delays
   - the number of emergency readmissions within 30 days
   - the number of people who receive an appropriate assessment of health and wellbeing on arrival
   - levels of staff and board dementia awareness and training
   - the number of people with dementia being prescribed antipsychotic drugs
   - examples of how care is being personalised (for example, use of Alzheimer’s Society’s This is me tool to understand a person’s needs and preferences)
   - examples of integrated care (for example, employing dementia support workers).

2. Monitor to use the annual dementia statement as part of its Risk assessment framework to identify and take action in hospitals where dementia care is inadequate

3. Care Quality Commission (CQC) to appoint a specialist dementia adviser and include dementia care indicators as part of its Intelligent Monitoring work to improve regulation of dementia services in hospital.
Fix Dementia Care: Key hospital statistics

This report is informed by Freedom of Information (FOI) requests of NHS hospital trusts in England and a survey of 570 people affected by dementia. The findings from these investigations can be found below.

Almost 60% of people we surveyed felt the person with dementia they know wasn’t treated with dignity or understanding while in hospital.

92% of people we surveyed said hospital environments are frightening for the person with dementia they know.

90% of people we surveyed said the person with dementia they know became more confused while in hospital.

There were 6,834 incidents of people with dementia falling in hospital last year.
Last year, 4,926 people with dementia were discharged from hospital between the hours of 11pm and 6am.

On average, people with dementia in hospital stay more than twice as long as other patients aged over 65.

Only 2% of those we surveyed said all hospital staff understood the needs of people with dementia.

At least 25% of hospital beds are occupied by people with dementia.

In 2013/14, £264.2m was wasted on poor dementia care in hospitals.
1 Introduction

There are over 700,000 people with dementia in England, with this figure expected to increase to around 850,000 by 2021 (Prince M, Knapp M et al, 2014). We know that the majority of people with dementia want to stay at home for as long as possible (Alzheimer’s Society and YouGov, 2014). However, at some point during the course of their condition, people with dementia may need to access hospital services, either as a planned admission or, as is more frequently the case, in an emergency.

People are not generally admitted for their dementia. Some of the most common reasons people with dementia are admitted to hospital include falls, broken/fractured hips or hip replacements, urinary tract infections, chest infections or stroke (Alzheimer’s Society, 2009). A significant number of these admissions could be avoided through better support in the community and greater integration of health and social care services.

In a reply to a written parliamentary question from MP Tracey Crouch (November 2014), figures from Department of Health revealed that people with dementia in hospital account for around 3.2 million bed days a year, with 25 per cent of hospital beds occupied by people with dementia at any one time. However, informal reports suggest this is a gross underestimate, with some hospitals stating that 40 to 50 per cent of their patients have dementia.

In Counting the cost, our report on hospital care (Alzheimer’s Society, 2009), we found that people with dementia often leave hospital with poorer health and wellbeing than when they arrived. Of the carers who responded to a survey for the report:

- 47 per cent said that being in hospital had a significant negative effect on the general physical health of the person with dementia, which wasn’t a direct result of the medical condition
- 54 per cent said that being in hospital had a significant negative effect on the person’s dementia symptoms, such as becoming more confused and less independent.

The respondents told us that the longer people with dementia were in hospital, the worse the effect on their dementia symptoms and their physical health. Hospital stays had led to weight loss, incontinence, exhaustion, pressure sores, bruising, reduced mobility, loss of communication skills and depression. Of the 60 per cent of people with dementia who went into hospital from their own home, only 36 per cent returned there, most of the rest were discharged into residential care.
In 2015, we investigated further to understand people’s experiences of care that led to these outcomes. The results were alarming. In a Facebook poll of over 570 carers, families and friends of people with dementia, we found that:

- only 2 per cent said that, in their experience, all hospital staff understood the specific needs of people with dementia
- 57 per cent said they felt the person they care for was not treated with understanding and dignity in hospital
- 90 per cent said they felt the person with dementia became more confused while in hospital
- 92 per cent thought hospital environments were frightening for the person with dementia.

From this survey, we also heard instances of people with dementia being treated with excessive force, of poor catheterisation leading to a urinary tract infection, of visits from family members and carers being denied, and of people not being changed or cleaned up after incontinence.

This report examines the experience of people with dementia from admission to discharge. By telling the stories of four families and their experiences, we outline what needs to change in order to fix dementia care in hospitals.
2 Admission

Joyce’s story: Hours of A&E agony

Joyce, 80, lives in a nursing home in Chester. She was diagnosed with Alzheimer’s disease in 2007.

In 2014, Joyce fell in the nursing home and broke her pelvis. Her daughter Louise took her to hospital, explained that she had fallen, and that her mum had dementia. They were forced to wait in a very busy A&E department for hours to be seen. The environment was bright, noisy and people kept brushing past Joyce’s wheelchair. Joyce became increasingly distressed, crying out loudly. Other people in the waiting room began to laugh and stare, with children asking questions about what was wrong with her.

Louise said, ‘On our second trip to hospital last July, after Mum had aspirated, I was so worried about how she would cope because after the first visit she was not herself for a long time. Once she was given the all-clear we had trouble getting Mum a drink as she needs thickened liquid to help her swallow. The A&E department didn’t have any thickener available for Mum to be able to have a drink.

‘On both trips into hospital I found myself having to constantly (and discreetly) explain to different staff that Mum had dementia. When Mum was admitted to A&E it was very distressing for both of us. It would have been less stressful if we could have waited in a quiet room away from the noise and onlookers. Hospitals need to be more dementia friendly and make sure all staff are aware of that person’s needs and how their dementia might affect them.’

Joyce, living with dementia
People with dementia are generally admitted to hospital to be treated for an injury or another condition, rather than because of their dementia. Memory loss, difficulties with communication, low mood, agitation, cognitive issues and frailty can make it harder for staff to understand the extent of the problem and offer the appropriate treatment and support.

A proper assessment of their needs on arrival is key to someone with dementia receiving appropriate care during their visit to hospital. However, many hospitals are not set up to deliver this quickly and sensitively, leaving people with dementia waiting in frenetic environments which they can find stressful and traumatic.

**Putting it right: Fast-tracking admission**

Hospital staff should identify people who have dementia or suspected dementia as quickly as possible and fast-track their assessment, so they can avoid a distressing wait in a dementia-unfriendly environment. Dementia awareness and training is essential to enable staff to triage people with dementia appropriately, communicating with them, their families and carers to understand their needs and offer appropriate care.

Hospitals are not only expected, but financially incentivised, to ensure at least 90 per cent of patients over 75 are screened for dementia on admission to hospital, and that these patients have a comprehensive assessment of their health and wellbeing, with referrals made to specialist services for follow-up as required. The assessment should consider the views of the person’s family or carer and their care plan to get the full picture.

However, even with these financial incentives, the most recent figures show that only 69 per cent of hospital trusts were doing this properly. While this was an increase of 14 per cent on the previous year, it means 46 hospitals were not delivering these basic minimum standards of care on admission. Additionally, and more alarmingly, the three poorest-performing hospitals were only screening, assessing and referring between 28 and 43 per cent of people admitted (NHS England, 2015).

Hospitals need to take urgent action to redesign admission pathways so people with dementia don’t have to wait for long periods of time in traumatising A&E environments and to ensure that they get a timely, comprehensive assessment of their needs.
3 Care in hospital

David’s story: When care is not personalised

Jill’s stepfather, David, is 64 and has frontotemporal dementia. He was admitted to hospital because of an agonising mouth abscess, which had developed during a long wait for an appointment to have two teeth removed. He became distressed and aggressive because of the pain, but when staff at his care home called for an ambulance, they were shocked when two police vans arrived to collect him.

Jill, who is from Denton, Greater Manchester, rushed to the home after she was told what had happened. She insisted that her father be taken to hospital in an ambulance. When he arrived there he was taken to a medical assessment unit and Jill explained why her father was so distressed. ‘I expected them to deal with his abscess as soon as possible, but he ended up being in hospital for months being moved from ward to ward,’ she says.

After six days on the medical assessment unit, David was moved to a general ward, which Jill describes as ‘horrendous’. She says, ‘It was an absolute nightmare. They kept forgetting to give him his medication and didn’t know how to deal with him. One time I went in to visit and four or five nurses were running around the ward after him – it was like a ‘Carry on’ film. He ended up with bruises on his arms after being grabbed by two big security guards. Dad used to become agitated because staff were trying to stop him roaming around picking things up, but all they had to do was sit him down and talk to him to calm him down.’
It is clear that too often hospitals are frightening and disorientating for people with dementia, as well as being places where their overall health and wellbeing often deteriorates rather than improves. A dementia-trained workforce working within dementia-friendly hospital environments can dramatically improve someone’s stay in hospital. However, we know that the majority of people with dementia want to stay at home, in the community, so it is important that people with dementia are able to leave hospital as soon as they are safe and well enough to do so (Alzheimer’s Society and YouGov, 2014).
Putting it right: Dementia support workers

To improve the experience of people with dementia and their carers in hospital, Leicester Royal Infirmary employs Alzheimer’s Society dementia support workers to provide practical and emotional support for people with dementia and their families and carers before, during and following a stay in hospital. The support workers talk through any concerns that people with dementia and carers may have and provide tailored information and guidance on how to live well with dementia. They liaise with hospital staff so that they understand an individual’s needs and are better able to care for them.

They help patients and carers to understand the hospital process, for example which staff members they might be in contact with or the hospital discharge process, and provide details of local support services available in the community when patients leave hospital. This vastly improves the quality of someone’s stay and ensures they are well supported in the community once they leave, helping prevent avoidable readmissions to hospital in the future.

Putting it right: Dementia-friendly environments

The hospital environment can be confusing and disorientating for people with dementia. Through its Enhancing the healing environment project, The King’s Fund found that changes to the physical environment can reduce falls and aggressive behaviour, improve staff recruitment and retention, and reduce overall costs.

Bradford Royal Infirmary has undertaken important work to make their hospital more dementia friendly. In the elderly care ward, the bland white walls of the bays and corridors have been painted with bold colours. Cinema seats provide spaces to watch films from the local archive and an office has been turned into a memory café where people can enjoy tea in the afternoon. On the orthopaedic ward, patients and visitors can also enjoy photographs of local scenes that encourage socialising and prompt memories. Social dining is encouraged in bed bays and new lighting schemes are being trialled to aid sleep patterns. These enhancements have improved patient wellbeing, enabling people with dementia to find their way around and reducing agitation.
It is vital that hospital staff at all levels, including porters, nurses, doctors and specialists, have a general knowledge and awareness of dementia. For staff who provide direct clinical care, an appropriate level of dementia training is essential so that they are able to understand people’s individual complex needs, including being able to determine whether they are in pain, in need of help, hungry, thirsty or simply uncomfortable.

At a national level, dementia awareness and training is being delivered through Health Education England’s (HEE’s) Dementia Awareness Training programme, which defines three levels of core competency:

- **Tier 1** – awareness-raising in terms of knowledge, skills and attitudes for all those working in health and care
- **Tier 2** – developing the knowledge, skills and attitudes of staff who have regular contact with people living with dementia
- **Tier 3** – enhancing the knowledge, skills and attitudes of key staff (experts) who work with people living with dementia, designed to support them to play leadership roles.

As of April 2015, HEE had provided tier 1 and tier 2 dementia training to 515,967 NHS staff, exceeding government targets, with the aim of embedding the training into ‘business as usual’. Most of the training was at tier 1. Going forward, there needs to be a greater focus on rolling out tier 2 and 3 training to ensure that NHS staff continue to receive the most advanced support available.
While dementia symptoms such as memory loss, difficulties communicating, low mood, agitation, cognitive issues and frailty can make a person’s care needs more complex, this does not justify our findings that people with dementia tend to stay in hospital more than twice as long as other people over the age of 65. Our Freedom of Information requests showed that last year the average length of stay for someone over 65 was 5.5 days, whereas for people with dementia it was 11.8 days (FOI request, 2015 – response from 73 trusts).

However these issues can be avoided and in many places they are. Last year, in the best-performing hospitals, the length of time people with dementia stayed was the same or only marginally longer than the length of stay for people over 65 without dementia. However, in the three worst-performing hospitals people with dementia stayed between five and seven times as long as other people over 65. The average stay in some of these hospitals for people with dementia was between 21.8 and 24.7 days (FOI request, 2015 – response from 73 trusts).

These extended stays and the variation between hospitals are unacceptable. The person with dementia suffers and it is expensive for the NHS. In 2013/14, excess days spent in hospital by people with dementia were estimated to have cost the NHS at least £155.3 million (CHKS, 2015). This is a shocking waste of millions of pounds – money that could be far better used supporting people to stay independent and healthy in their own homes. This issue must be addressed.

Putting it right: Personalising care

Alzheimer’s Society developed This is me, a leaflet for use across care settings for people with dementia to provide background information on their needs, preferences, likes, dislikes and interests. It can also provide information about other conditions they might have. This information enables clinical staff to see the person as an individual and deliver person-centred care tailored specifically to their needs. It can help overcome problems with communication, preventing issues such as malnutrition and dehydration.

Carers play an important role in ensuring people with dementia get the right care and support. Traditionally, however, carers have been limited to hospital visiting hours. John’s campaign, founded in 2014, calls for carers to have the right to stay with people with dementia throughout their time in hospital. Over 200 hospitals have already signed up to the campaign, enabling carers to be there when they are needed most, contributing key information and support to ensure the person with dementia’s needs and preferences are met.
Annara’s story: A fatal fall

In March 2014, during a stay in hospital, Annara’s mother, Iris, fell out of bed and landed directly on her face, leaving a deep cut and severe bruising. Annara called the hospital and was told Iris had experienced a minor fall and had a slight cut on her head.

When Annara’s sister, Hazel, visited her mother, she found her heavily bandaged with purple bruising around her chin and eyes. They believe Iris must have injured her mouth, as the inside was black.

Annara asked the hospital staff to explain how her mum had fallen out of bed, but this was never provided. When Iris returned home, there was no mention of the fall on the medical notes and no follow up with the GP had been arranged. Iris started getting dizzy spells and stopped eating and drinking. She passed away on 31 July 2014.

Annara said: ‘Mum was never the same after she fell in hospital. She started getting dizzy spells, hardly drank or ate, was nearly always in bed and found it hard to follow simple instructions. I was astounded it was dismissed as minor incident – told by hospital staff she had a “slight cut on her head.” You expect to come out of hospital feeling better, not in a worse state than when you went in. The entire episode has left our family broken. I am in no doubt it contributed to Mum’s death three months later.’

Annara
A key marker of the quality of care someone receives in hospital is the likelihood of them having a fall during their stay. Inconsistent hospital recording of the numbers of people with dementia who have fallen means this data was only available for a quarter of hospitals, but, even in this small sample, 6,834 falls were reported last year. In these hospitals, 28.3 per cent of people aged over 65 who had a fall were people with dementia, but these numbers were as high as 52.2 to 70.6 per cent in the three worst-performing hospitals (FOI request, 2015 – response from 38 trusts).

On average, people with dementia spend nearly four times as long in hospital following a fall (CHKS, 2015). The resulting frailty and an extended stay in hospital can increase the likelihood of them going into a residential home or worse.

**Putting it right: preventing falls**

There will always be occasions where patients experience a fall while in hospital but these should be rare and treated extremely seriously. Hospital boards should receive reports of the number of falls on wards and take action to reduce numbers – for example, through dementia training for staff, adaptions to the hospital environment and having a falls policy in place that outlines how care should be delivered to prevent falls and what to do when one occurs. In the event of a fall, carers should be informed as soon as possible and all necessary measures should be taken to ensure that it doesn’t happen again.

The impact of falls is not only devastating for people with dementia and their families but also costly to the NHS. In 2013/14 alone, falls in hospital of people with dementia were estimated to have cost the NHS at least £15.9 million (CHKS, 2015). These millions could be invested in staff training and adaptions to the environment, saving people with dementia the trauma of a fall and the resulting complications.
Kay and Sally-Ann are full-time carers for their dad, Geoff, who is 86 and was diagnosed with vascular dementia in 2013.

After falling at home, injuring his elbow and head and fracturing his kneecap and six ribs, Geoff stayed in hospital for nearly a month. Achieving a co-ordinated and timely discharge was a major challenge.

Two weeks into his stay, Kay and Sally-Ann were told that Geoff was ready to go home – but there was no mention of a physiotherapist for his knee and his elbow bone was still exposed. They were assured that he would be able to walk up and down stairs. However, when they arrived at the hospital to collect him, a changeover of staff on the ward meant staff didn’t know about Geoff’s treatment or history and didn’t have a care plan prepared, so he was unable to leave.

On a number of occasions, Geoff would prepare to leave and then staff would change their minds. In the end an operation was scheduled to stitch up Geoff’s elbow.

Following the operation, when Geoff was ready to be discharged, the hospital failed to give Sally-Ann and Kay advance notice despite them repeatedly saying that they would need plenty of warning as they lived an hour away. They found Geoff alone in the discharge lounge with all his medication. He had started to take all his tablets as they had his name on them and he thought it was the right thing to do.

Kay told us, ‘My dad received really quite dysfunctional care. Most of the staff didn’t seem to understand dementia and communication was poor. We had to endlessly repeat his specific care requirements as there was no continuity. When he was finally ready to leave hospital, it was beyond a joke to find Dad alone in the discharge lounge surrounded by half-opened boxes of his medication. He could very easily have accidently overdosed.’
Time in hospital often has a negative effect on the health and wellbeing of people with dementia; any delays in discharge can cause further deterioration. However, being discharged prematurely, following poor care or without the adequate community support in place, can lead to someone becoming ill or falling and being readmitted to hospital, often in a worse condition than before. It can also lead to people being discharged to a care home despite research showing that 85 per cent of people with dementia want to be supported to live in their own home throughout their condition (Alzheimer’s Society and YouGov, 2014). Substandard care and poor discharge co-ordination can fundamentally change the lives of people with dementia and their families for the worse – it’s vital that we get this right.

Putting it right: Discharge co-ordination

All hospitals should have a discharge policy that takes the needs of people with dementia into account. People should be assigned a discharge co-ordinator who ensures they have a health and social care assessment and that an appropriate support package is put in place to meet the needs and aspirations of the person with dementia and their carer. The date and time of discharge should be discussed and arranged with the person and their carer with at least 24 hours’ notice, along with transport to their home or care home. No one should be left alone with their medication.

There is huge variation and unacceptable practice across the country when it comes to discharge. The following figures have been calculated from a series of Freedom of Information requests.

- Last year, 4,926 people with dementia were discharged between 11pm and 6am. In the three worst-performing hospitals, four to five people were being discharged overnight per week (FOI request, 2015 – response from 68 trusts). Discharge at night is unsafe, disorientating and distressing. People are more likely to leave without relevant information, the correct medication or the right support in place because staff are not on duty to discharge them properly. Similarly, GPs and support workers are less accessible to help someone resettle or help if they have a problem. This dangerous practice must stop.

- Last year, 24.4 per cent of people over the age of 65 who experienced delayed discharge had dementia. In the three worst-performing hospitals this figure was between 39.4 and 65.4 per cent (FOI request, 2015 – response from 28 trusts).

- Last year, 7.4 per cent of people over 65 who were readmitted to hospital within 30 days were people with dementia. However, in the worst-performing hospital 52.3 per cent had dementia, and in the next three worst-performing hospitals, the figure was between 18.7 and 24.4 per cent (FOI request, 2015 – response from 73 trusts).
• Last year 7.7 per cent of people with dementia admitted to hospital from home were discharged to a care home following their stay. In the three worst-performing hospitals, between 30.4 and 39.5 per cent were admitted from home and discharged to a care home (FOI request, 2015 – response from 65 trusts).

No one wants to be cared for in a hospital where the quality of care they receive means they are more likely to end up in a care home afterwards. Nor do people want to go somewhere where they might be kept in too long or discharged in the middle of the night. These incidents are not only potentially catastrophic for people with dementia and their families but waste millions of pounds. In 2013/14, it was estimated that emergency readmissions cost the NHS £93 million (CHKS, 2015). Urgent action needs to be taken to improve discharge for people with dementia and ensure public money is spent on providing integrated health and social care packages for people with dementia on discharge from hospital.
6 Conclusion: What needs to change

The experiences of David, Joyce, Iris and Geoff highlight the devastating emotional and physical toll of poor dementia care in hospital on those with the condition and their families. Nobody should have to go into a hospital where statistics suggest they are five times more likely to have a fall than at the next nearest hospital, or are likely to have to stay twice as long. There is also no excuse for wasting £264.2 million a year on extra care needed because of falls, unnecessary extra days spent in hospital and avoidable emergency readmissions of people with dementia (CHKS, 2015). This money could be much better spent on supporting people with dementia to live well in the community.

Putting it right: A dementia strategy

The London Borough of Kingston and Richmond has one of the highest life expectancies in England. As a result, nearly half of patients over the age of 75 at Kingston Hospital have dementia – double the national average. The numbers are set to grow and, in January 2014, the hospital trust’s first ever dementia strategy was approved by its board.

The strategy was developed with patients, carers, staff, voluntary and community groups and reflects all of their needs when caring for patients with dementia. The strategy has five areas of focus:

- **Early diagnosis, excellent clinical treatment and care** – ensuring staff diagnose dementia and delirium at the right time and provide the right support afterwards.

- **Positive relationships of care** – ensuring a culture of excellent, compassionate care provided by staff who are confident in their roles.

- **Involved and supported carers** – ensuring a culture that always involves and engages carers as partners in care.

- **Active days and calm nights** – enabling patients to maintain their rituals and routines despite being in hospital and supporting patients to engage in meaningful activities.

- **Environments of care** – creating a truly dementia-friendly hospital site with secure, safe, homely and comfortable social and therapeutic environments.
The hospital runs therapeutic activity sessions for patients with dementia every day, including painting, listening to music, craft, knitting and jigsaw puzzles. The sessions are led by hospital staff along with a group of trained dementia activity volunteers. In partnership with Home Instead Senior Care, the trust also runs free, fortnightly memory cafés at the hospital. Patients, relatives and carers from the hospital and the local community can come along to find out more about issues related to memory loss, get involved with activities, receive practical advice and support, and talk with professionals about their concerns.

In addition, all inpatients with dementia have a forget-me-not flower symbol above their beds so that staff are aware that they have the condition. A Dementia and Delirium Team, which includes carer representatives, meets regularly and leads on the work to improve dementia care. The hospital now has one of the largest volunteer dining companion schemes in the NHS and more than 300 people, including non-clinical staff, have been trained to provide additional help and support at mealtimes.

To ensure it responds to the needs of patients, their families and carers, the hospital has adapted its Friends and Family Test to enable carers to feed back, helping the hospital to make further changes to the care and service it provides. The trust has signed up to John’s campaign and provides facilities to ensure that carers and families can stay overnight with their loved ones in hospital. This has now been extended to theatres, with carers and relatives able to go to theatre with the person with dementia and be there when they come round in recovery.

In July 2014, the trust received national recognition of its work to transform the care provided to patients with dementia at the Patient Safety and Care Awards. It has also launched a major fundraising appeal to raise £750,000 to make wards more dementia friendly and develop a new dementia centre at the hospital.
7 Recommendations

Hospitals have a duty to be transparent and accountable to their patients, and to continually monitor and improve dementia care. It shouldn’t take investigative work by Alzheimer’s Society to lift the lid on poor and variable dementia care – information regarding the quality of dementia care at local hospitals should be in the public domain. Health regulators need to play their part too, ensuring they are upholding the highest standards in dementia care. It is on these grounds that Alzheimer’s Society is making the following recommendations to fix dementia care in hospitals. These actions must be built into the forthcoming implementation plan for the Prime Minister’s challenge on dementia 2020 to ensure unified, system-wide change.

Recommendation 1: All hospitals to publish an annual statement of dementia care

Speaking in October 2015, Jeremy Hunt, Secretary of State for Health, stated, ‘By being more transparent than ever before about crucial services, we really can make NHS patients the most powerful in the world.’ A simple way for hospitals to be more transparent and accountable is by publishing a yearly dementia statement. On the recommendations of the Francis Inquiry and the National audit of dementia care in general hospitals, boards and directors of hospitals should already be receiving and assessing key information regarding the state of dementia care in their hospital and acting accordingly to guard against catastrophic breakdowns in care, such as those seen in Mid Staffordshire, and making improvements (Royal College of Psychiatrists, 2013). This information should include:

- satisfaction levels among patients with dementia and their carers
- figures showing the number of falls
- the number of inappropriate discharges, including those between the hours 11pm and 6am, with less than 24 hours’ notice or with significant delays
- the number of emergency readmissions within 30 days
- the number of people who receive an appropriate assessment of health and wellbeing on arrival at hospital
- levels of staff and board dementia awareness and training
- the number of people with dementia being prescribed antipsychotic drugs
- examples of how care is being personalised (for example, use of the Alzheimer’s Society’s This is me tool to understand a person’s needs and preferences)
- examples of integrated care (for example, employing dementia support workers).
This reporting should be shaped into an annual statement that is discussed at the hospital trust’s AGM and published on its website. This will allow people to see the quality of dementia care in their area. If all hospitals have a dementia statement in place it will help motivate them to implement change where needed to ensure they provide the specialist care that people with dementia need.

As per the recommendations in the National audit of dementia care in general hospitals, hospitals without a dementia strategy, a dementia champion at board level or defined process to review the quality of dementia care in their hospital, need to act immediately to ensure they have these governance structures in place so that they can collect, consider and publish a statement on dementia care and act on the findings (Royal College of Psychiatrists, 2013). There should also be a defined dementia care pathway from admission to discharge and an identified senior clinician to oversee its implementation – as well as plans in place to deliver dementia training for staff, make the hospital environment more dementia friendly and make care more personalised. By joining the Dementia Action Alliance and committing to delivering on the National dementia declaration and Dementia friendly hospitals charter, hospitals can get support from peers to develop these essential arrangements to deliver the best quality dementia care.

**Recommendation 2:**
Monitor to use the annual dementia statement as part of its Risk assessment framework to identify and take action in hospitals where dementia care is inadequate

Monitor, the government regulator of health services in England, uses its Risk assessment framework (Monitor, 2015) to judge whether hospitals are financially stable and delivering high quality services. If care is inadequate, Monitor requires hospitals to take action to improve services. This can include pairing the hospital with a high-performing one, creating and implementing an improvement plan and changing the leadership of the hospital.

The Risk assessment framework considers the quality of care for many conditions including learning disabilities, heart disease and cancer. However, despite at least a quarter of hospital beds being occupied by someone with dementia at any one time, the framework does not consider dementia. Monitor must amend its framework to consider the information contained in the annual dementia statement. This would provide Monitor with crucial evidence of the quality of dementia services in individual hospitals and give people affected by dementia an assurance that, in areas where care is not good enough, urgent action will be taken to improve it.
Recommendation 3:
Care Quality Commission (CQC) to appoint a specialist dementia adviser and include dementia care indicators as part of its Intelligent Monitoring work to improve regulation of dementia services in hospital

CQC works alongside Monitor to regulate hospitals in England. A key part of its work is inspecting the performance of hospitals. CQC prioritises its inspections through its Intelligent Monitoring programme (Care Quality Commission, 2015), which considers 155 indicators to determine how safe, effective, caring, responsive and well led a hospital is. Indicators consider everything from mortality rates to diagnostic waiting times and patient and staff satisfaction surveys. The poorest-performing hospitals are prioritised for inspection. Following an inspection, hospitals are given a rating of outstanding, good, needs improvement or inadequate. CQC can impose fines, place restrictions on service delivery and set improvement plans for underachieving hospitals.

Although CQC’s review of dementia care in hospitals in 2014, Cracks in the pathway (Care Quality Commission, 2014), found that people with dementia are ‘likely to experience poor care at some point along their care pathway’ and that the level of variability in care is unacceptable, CQC does not include any indicators to directly address the quality of dementia care in its Intelligent Monitoring work. This undermines the usefulness of the rating system for people affected by dementia.

CQC must rectify this by including the components of the annual dementia statement in its Intelligence Monitoring work. This work should be driven forward by a national specialist adviser for dementia care, as committed to in the Cracks in the pathway report. Recruitment to this post must happen immediately. This combination of actions will ensure CQC adequately assesses dementia care across hospital settings, identifies the right steps to improve care and gives people affected by dementia an assurance of the quality of dementia care they can expect in their local hospital.
This report draws on:

- Freedom of Information requests to NHS hospital trusts
- a Facebook survey of people with dementia, their families and carers
- in-depth interviews with carers of people with dementia
- public policy documents
- emerging good practice examples
- research commissioned by Alzheimer’s Society and YouGov
- existing indicators, such as Commissioning for Quality and Innovation (CQUIN) indicators.

Freedom of Information requests were submitted to 163 NHS hospital trusts in October 2015. We received responses from 87 trusts (53 per cent). Inconsistent data coding at hospital trusts meant that trusts did not hold figures for all requests. As a result, some calculations used in this report are based on smaller sample sizes, particularly those comparing the experiences of people over the age of 65 and people with dementia. The following table details the responses used in each issue area. While a greater response would have been welcome, the sample size does not detract from the shocking variation in the quality of dementia care found across the country and examples of poor care.

<table>
<thead>
<tr>
<th>Issue area</th>
<th>Response following data cleansing</th>
</tr>
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<tbody>
<tr>
<td>Length of stay</td>
<td>73</td>
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<tr>
<td>Falls</td>
<td>38</td>
</tr>
<tr>
<td>Readmissions</td>
<td>73</td>
</tr>
<tr>
<td>Overnight discharge</td>
<td>68</td>
</tr>
<tr>
<td>Delayed discharge</td>
<td>28</td>
</tr>
<tr>
<td>Discharge to care home</td>
<td>65</td>
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</table>
Alzheimer’s Society commissioned CHKS to provide an updated version of An economic analysis of the excess costs for acute care for patients with dementia. Calculations were made using Hospital Episode Statistics data from 2013/14. The report notes that inconsistent hospital coding of dementia means the calculations are likely to be an underestimate.

The Facebook survey was conducted in August 2015. There were over 570 respondents including people with dementia, their families and carers. It was a self-selecting sample that provides a snapshot of the experiences of people with dementia in hospital rather than a definitive evaluation.
Appendix 2: References


Alzheimer’s Society is the UK’s leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

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