National Audit of Dementia
Care in General Hospitals 2018-2019

Accessible report
Authors
This report was produced by Oliver Corrado, Beth Swanson, Chloe Hood, Aimee Morris, Samantha Ofili, Jhermaine Capistrano, Jessica Butler and Lori Bourke. We would like to thank Hilary Doxford and Chris Roberts, co-founders of the 3 Nations Dementia Working Group and members of the National Audit of Dementia Steering Group, for reviewing and commenting on the report.

Please see our website for full details of the Steering Group members and the Project Team.

Partner Organisations
Age UK
Alzheimer’s Society
British Geriatrics Society (BGS)
John’s Campaign
National Dementia Action Alliance (NDAA)
Royal College of Nursing (RCN)
Royal College of Physicians (RCP)

Acknowledgements
We would like to thank everyone who contributed to this report. We would especially like to mention:

• The carers for people with dementia and staff working in hospitals who completed a questionnaire for this round of the audit.
• The audit leads, champions, and clinical audit staff for their hard work organising the data collection in their hospitals (a list of participating hospitals is on our website).
• The participants in the Service User Review Panels held following Round 3, for their contribution to the content of Round 4 (a report on the panel discussions is on our website).
• All the members of the Steering Group and especially our Chair, Peter Crome.

Artwork
Many thanks to Tracy Shorthouse for permission to use her artwork ‘Autumn Leaves’ on the cover of the accessible version of the report. All entries in the NAD art prize can be seen on our website. We would like to thank all entrants for sending us their impressive work and permitting us to display it.


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The purpose of this report

The National Audit of Dementia (care in general hospitals) reported for the fourth time in July 2019. This document is a shorter version of the national report’s findings. It presents some of the main findings from the audit in a user-friendly way. Why the findings are important to people with dementia is detailed throughout the report. Recommendations related to these findings are also given in this report.

The report for the fourth round of the National Audit of Dementia was published in July 2019, this can be downloaded here.

How were people with dementia involved?

Our Steering Group includes representatives with experience of living with dementia, or providing care for a person with dementia. We also had advice on the content and layout of this accessible report from Hilary Doxford and Chris Roberts, co-founders of the 3 Nations Dementia Working Group and members of the National Audit of Dementia Steering Group.
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Introduction
Dementia is the umbrella term used for conditions and symptoms caused by illnesses which damage the brain. Symptoms vary but may include memory loss, difficulties with thinking, language and problem solving, and changes in mood and behaviour.

Being in hospital can be especially difficult for a person affected by dementia, who will be in an unfamiliar environment as well as having an illness or injury. Common reasons why people with dementia are admitted to hospital include falls, hip fractures, stroke, urinary tract infections, and respiratory infections.

There are 850,000 people living with dementia in the UK and this is predicted to rise to 2 million by 2051. Improving dementia care is a national priority for health services in England and Wales. NHS England/NHS Improvement supports the Dementia Friendly Hospitals charter of the Dementia Action Alliance. The charter provides guidelines for hospitals to make the experience of being in hospital better for people living with dementia.
Previous rounds of reporting
There have been three rounds of the National Audit of Dementia carried out between 2008 and 2017. Each round of audit has looked at the quality of care received by people with dementia while in hospital.

The report from the first round of audit found that hospitals needed to have a detailed approach to the care of people with dementia.

Round two of the audit found that some improvement had taken place in assessment and discharge planning. There was increased support for dementia in hospital.

The third round of audit showed that many hospitals had implemented changes to support the care of people with dementia. This included training for staff. However, delirium assessments were inconsistent.

Visit our website for reports from the previous rounds of the audit.
The fourth National Audit of Dementia collected information in 2018 and reported in 2019.

195 (out of 201) acute general hospitals took part in this round of the audit.

Information collected from hospitals

A checklist asking for:
- Hospital guidelines which support the care of people with dementia
- Support hospitals had in place for people with dementia, carers and staff
- Training provided for staff

Information from the casenotes of 50 patients with dementia, admitted to hospital for at least three days discharged in April 2018:
- What happens when the patient arrives and leaves hospital
- Care plan
- Physical and mental health assessments.

We did not ask for any personal information such as name, date of birth, address or postcode, to ensure that the information was anonymous.
Carer questionnaires were given to carers and family members visiting people with dementia. It asked about:
- Patient care
- Communication
- Support for the carer

Staff questionnaires were given to all clinical staff working with adult inpatients, plus ward administrators and ward clerks. It asked about:
- Communicating with carers, other staff and people with dementia
- Training in dementia care
- Supporting the needs of people with dementia
Key findings and recommendations

Assessments for delirium

58% of patients with dementia were examined to see if they had delirium

66% of patients with indications of delirium (detected using a screening tool or noted during admission) went on to have a full assessment

81% of patients who received a full assessment had a confirmed diagnosis of delirium made during their admission

Recommendation for Medical Directors and Directors of Nursing:

• Ensure that people with dementia admitted as an emergency are assessed for delirium
• Consider the symptom of pain as a contributing factor in delirium

Use of personal information

36% of personal information documents included factors which caused the person distress

32% of documents included actions which could calm the person with dementia

Recommendations for Directors of Nursing:

• Ensure that assessment of people with dementia includes information about factors that cause distress
• Ensure that assessment of people with dementia includes steps that can be taken to prevent distress
Dementia awareness training

103 hospitals had information on the amount of staff who had dementia awareness training

Recommendations for Trust Chief Executive Officers:
- Demonstrate that all staff providing care for people with dementia receive mandatory training in line with their role
- Ensure that delirium and its relationship to dementia is included in the training
- Record the number of staff who have received dementia training

Trust/Health Board involvement in dementia care

37% of hospitals could identify patients with dementia who were readmitted to hospital
40% of hospitals could identify patients with dementia whose discharge had been delayed
64% of hospitals could identify patients with dementia who had a fall while in hospital

Recommendation for Trust Executive Directors:
Ensure that information is presented to the Board that identifies the number of patients with dementia who experience a fall during admission, a delayed discharge, or readmission within 30 days of discharge
Further results from the National Audit of Dementia Round Four

In this section you will find more of the results from the national report. There are seven themed chapters in the national report which are also explored in this report.

- Carer feedback on quality of care
- Assessment
- Information and communication
- Staffing and training
- Provision of suitable food and drink
- Leaving hospital
- Procedures to support care
## Carer feedback on quality of care

### Why it matters

Carer involvement during hospital admission is important to people with dementia to help support care delivery. A carer questionnaire was given to carers visiting people with dementia in hospital. Questions were asked about aspects of care delivery and support for the carer.

### Finding

<table>
<thead>
<tr>
<th>Finding</th>
<th>Round 3</th>
<th>Round 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of carers who said that the person they care for was treated with respect by hospital staff</td>
<td>76%</td>
<td>78%</td>
</tr>
<tr>
<td>Percentage of carers who said that the overall quality of care the person they care for received while in hospital was ‘excellent’ or ‘very good’</td>
<td>69%</td>
<td>72%</td>
</tr>
<tr>
<td>Percentage of carers who thought that hospital staff were well informed and understood the needs of the person they care for</td>
<td>47%</td>
<td>51%</td>
</tr>
<tr>
<td>Percentage of carers who thought that the person they look after was given enough help with personal care from hospital staff</td>
<td>56%</td>
<td>59%</td>
</tr>
<tr>
<td>Percentage of carers who were ‘very satisfied’ with the support they receive from the hospital to help them in their role as a carer</td>
<td>50%</td>
<td>54%</td>
</tr>
</tbody>
</table>
### Assessment

#### Why it matters

This theme looks at the physical and mental health assessments received by people with dementia when admitted to hospital. Assessments can improve the outcomes of patients, including survival and returning home after admission. In the fourth audit there was a slight improvement in the number of patients receiving physical assessments.

<table>
<thead>
<tr>
<th>Finding</th>
<th>Round 3</th>
<th>Round 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Percentage of patients who had a mental health assessment</td>
<td>New for round 4</td>
<td>54%</td>
</tr>
<tr>
<td>Percentage of patients who were asked if they were in any pain</td>
<td>83%</td>
<td>85%</td>
</tr>
<tr>
<td>Percentage of patients thought to have delirium who had a full delirium assessment</td>
<td>New for round 4</td>
<td>76%</td>
</tr>
<tr>
<td>Percentage of patients who had their continence assessed</td>
<td>88%</td>
<td>89%</td>
</tr>
<tr>
<td>Percentage of patients who received a pressure ulcer assessment</td>
<td>96%</td>
<td>96%</td>
</tr>
<tr>
<td>Percentage of patients who were assessed to see how well they could carry out daily activities</td>
<td>90%</td>
<td>91%</td>
</tr>
</tbody>
</table>

### Why it matters

This theme looks at the physical and mental health assessments received by people with dementia when admitted to hospital. Assessments can improve the outcomes of patients, including survival and returning home after admission. In the fourth audit there was a slight improvement in the number of patients receiving physical assessments.
What do staff think needs to be done in assessment to improve dementia care?

“Identifying earlier and putting in place measures to prevent delirium, dehydration, and constipation.”

*Allied Healthcare Professional*

“Utilising an appropriate pain assessment tool e.g. pain assessment in advanced dementia.”

*Registered Nurse Band 7*

What should hospitals be doing?

**Medical Directors and Directors of Nursing** should make sure that people with dementia admitted as an emergency are assessed for delirium. Staff should also consider pain in this assessment.
**Information and communication**

**Why it matters**

This theme looks at personal details recorded about the person with dementia. This helps the hospital to provide better care to individual patients with different needs. This theme also looks at how important information about the person was shared with hospital doctors and nurses.

<table>
<thead>
<tr>
<th>Finding</th>
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</thead>
<tbody>
<tr>
<td>Percentage of patients who had ways they could be supported with personal care recorded in their notes</td>
<td>56%</td>
<td>57%</td>
</tr>
<tr>
<td>Percentage of staff who said that they ‘frequently’ met as a team to discuss the care needs of people with dementia</td>
<td>50%</td>
<td>51%</td>
</tr>
<tr>
<td>Percentage of hospitals which use a visual symbol to indicate that the patient has dementia</td>
<td>99%</td>
<td>97%</td>
</tr>
<tr>
<td>Percentage of carers who said that they were ‘definitely’ involved in decisions about care</td>
<td>48%</td>
<td>51%</td>
</tr>
<tr>
<td>Percentage of patients who had details to help them communicate recorded in their notes</td>
<td>43%</td>
<td>48%</td>
</tr>
<tr>
<td>Percentage of patients who had personal details and likes/dislikes recorded in their notes</td>
<td>48%</td>
<td>49%</td>
</tr>
</tbody>
</table>
What do carers say about communication?

“...We were told about the Butterfly Scheme in the hospital but when we approached the nurses they made it clear that they didn't want to encourage it.”

“Staff treated my family member with dignity and respect at all times, he was treated as an individual and his care was very person centred...”

“I feel that the staff do not want to take care of the old and confused patients in this hospital. As soon as they have had enough, they contact family even secretly to help deal with the patient. None of them are trained [or] know how to deal with the patient. They just don’t care anymore. Very upset by this.”

What should hospitals be doing?

Directors of Nursing should make sure that assessment of people with dementia includes information about factors that can cause distress or agitation.

Trust Chief Executive Officers should make sure that there is clear communication with families and carers of people with dementia.
Staffing and training

Why it matters

This theme looks at whether there were enough staff to provide care and what kind of dementia awareness training hospitals have in place. Hospitals need the correct number of doctors and nurses with correct skill sets to deliver safe and effective care for patients with dementia, who may have additional needs.

<table>
<thead>
<tr>
<th>Finding</th>
<th>Round 3</th>
<th>Round 4</th>
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</thead>
<tbody>
<tr>
<td>Percentage of nurses who said they had received some form of dementia training</td>
<td>86%</td>
<td>91%</td>
</tr>
<tr>
<td>Percentage of doctors who said they had received some form of dementia training</td>
<td>65%</td>
<td>84%</td>
</tr>
<tr>
<td>Percentage of healthcare assistants who said they had received some form of dementia training</td>
<td>86%</td>
<td>90%</td>
</tr>
<tr>
<td>Percentage of hospitals which were able to provide information about the total number of staff who had received dementia training</td>
<td>New for Round 4</td>
<td>53%</td>
</tr>
<tr>
<td>Percentage of hospitals which use a tool to show how many staff members should be on a ward</td>
<td>99%</td>
<td>97%</td>
</tr>
</tbody>
</table>
What do carers and staff say about training?
“Higher staffing levels to provide one-to-one for those patients who need it. This would increase staff morale and help the patient, as well as other patients as they will be given more help from the nurse.”

Doctor

“Personally, I think full training needs to be given to all staff who are not educated on dementia patients and their needs. I feel it is not fair on both the uneducated staff of dementia and the patient.”

Healthcare Assistant

“I can't thank nursing staff enough they have all been fantastic. My husband has always been spotless and been shaved. They are all wonderful.”

Carer

What should hospitals be doing?

Trust Chief Executive Officers should make sure that all staff providing care for people with dementia receive dementia training.

Trust Chief Executive Officers should make sure that external providers of services to the hospital have received training in dementia appropriate to their role.
Provision of suitable food and drink

**Why it matters**
This theme looks at whether hospitals can provide suitable food and drink services for people with dementia, how staff report this is working, and whether carers are able to provide support during mealtimes. Lack of food and drink can be a serious issue for older people when in hospital. It can lead to further illness and complications.

<table>
<thead>
<tr>
<th>Finding</th>
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</thead>
<tbody>
<tr>
<td>Percentage of staff who said that the food and drink needs of people with dementia were discussed when staff changed shifts</td>
<td>80%</td>
<td>77%</td>
</tr>
<tr>
<td>Percentage of hospitals which have protected mealtimes in place</td>
<td>98%</td>
<td>98%</td>
</tr>
<tr>
<td>Percentage of hospitals which allow carers to visit any time to help the person they care for with meals</td>
<td>89%</td>
<td>96%</td>
</tr>
<tr>
<td>Percentage of hospital staff who said that food that can be eaten without a knife and fork was available ‘always’ or ‘most of the time’</td>
<td>65%</td>
<td>72%</td>
</tr>
<tr>
<td>Percentage of hospital staff who said that snacks were available ‘always’ or ‘most of the time’ between meals</td>
<td>73%</td>
<td>75%</td>
</tr>
</tbody>
</table>
What do carers and staff say about food and drink?

“What nutritional needs should/could be communicated better. Patients who require support with feeding should not have to wait until their food is cold!”  

*Allied Healthcare Professional*

” The meals were not consistent. One night there was only cornflakes left for [patient].”

*Carer*

“…Sometimes those who are to be fed are given cold food as they have to wait so long to be fed because staff are dealing with other matters. Sometimes the tray of food is removed by the kitchen staff before the patient has been fed…”

*Carer*

What should hospitals be doing?

**Directors of Nursing** should make sure that nurses talk about the food and drink needs of patients with dementia during shift handovers.

**Trust Chief Executive Officers** should make sure that both finger foods and snacks are provided for people with dementia at all times.
Leaving hospital

Why it matters
This theme focuses on patient discharge from hospital. This includes looking at how plans are made when patients are ready to leave the hospital, and whether people with dementia and their carers are involved in planning for discharge. Planning and discussions between hospital staff, carers and the person with dementia is key to a smooth discharge from hospital.

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<tr>
<th>Finding</th>
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</thead>
<tbody>
<tr>
<td>Percentage of hospitals that have a specific person who planned discharges for people with dementia</td>
<td>96%</td>
<td>92%</td>
</tr>
<tr>
<td>Percentage of discharge plans that contained up to date information about the patient’s mental health</td>
<td>45%</td>
<td>44%</td>
</tr>
<tr>
<td>Percentage of family members or carers who were given less than 24 hours’ notice that the person with dementia would be leaving hospital</td>
<td>27%</td>
<td>28%</td>
</tr>
<tr>
<td>Percentage of patients who had a discussion with hospital staff about the support they would need outside of hospital</td>
<td>54%</td>
<td>57%</td>
</tr>
<tr>
<td>Percentage of patients who had their level of thinking and understanding assessed on discharge</td>
<td>22%</td>
<td>11%</td>
</tr>
</tbody>
</table>
What do carers and staff say about leaving hospital?

“I was always kept up to date with all information, so we could discharge plan well in advance.”

Carer

“We were not told when my father would be discharged from hospital and were never given any information regarding his progress. We always had to ask what was happening.”

Carer

“There is much about safeguarding and mental capacity for doctors in mandatory training but nothing specific that I am aware of for dementia - raising awareness of what resources are available for hospital staff would be helpful.”

Doctor

What should hospitals be doing?

**Hospital discharge teams** should make sure they talk to people with dementia and their carers about where they are being discharged to. They should also talk about their needs once they have left hospital.

**Medical Directors** should make sure NICE guidance on continuity of care and the transmission of information at transfer home is being followed.
Procedures to support care

Why it matters
This theme looks at how hospitals plan and review care for people with dementia. Effective planning by hospitals ensures that people with dementia receive the best and most appropriate care when in hospital.

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<tr>
<th>Finding</th>
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</thead>
<tbody>
<tr>
<td>Percentage of hospital wards which have a dementia champion. Dementia champions are specially trained staff who promote the needs of people with dementia</td>
<td>94%</td>
<td>89%</td>
</tr>
<tr>
<td>Percentage of hospitals which have dementia working groups to look at the care of people with dementia</td>
<td>94%</td>
<td>92%</td>
</tr>
<tr>
<td>Percentage of hospitals which reported that they moved patients with dementia at night and this was a concern</td>
<td>38%</td>
<td>59%</td>
</tr>
<tr>
<td>Percentage of hospitals which have an overall plan called a care pathway in place or being developed. This sets out how to provide the best care for people with dementia</td>
<td>87%</td>
<td>92%</td>
</tr>
<tr>
<td>Percentage of hospitals which looked at the hospital environment to see how well suited it was for people with dementia</td>
<td>43%</td>
<td>53%</td>
</tr>
</tbody>
</table>
What do carers and staff say about procedures to support care?

“It is important for people with dementia to NOT have to keep orientating themselves in a new environment, bed moves in the hospital should be kept to a minimum.”

Allied Healthcare Professional

“Staff were approachable and had time to talk. We were actively involved in decisions about referring to Social Services and for an occupational therapist.”

Carer

What should hospitals be doing?

Trust Chief Executive Officers should make sure that hospital wards are safe and friendly spaces for people with dementia. Changes should be made if they are not.

Trust Chief Executive Officers, Medical Directors and Directors of Nursing should make sure that hospitals have a policy in place to reduce the number of patients being moved at night.

Trust Executive Directors should make sure that they know how many people with dementia have experienced a fall during their admission, a delay to their discharge, and readmission within 30 days of discharge.

Trust Dementia Leads should make sure that people with dementia and carers are represented on a Dementia Working Group or Patient Experience Group.
Other reports from Round Four

This accessible report shows the key findings from the full National Report. The National Report also contains scores for each hospital, based on their results. You can see the National Report [here](#).

Each participating hospital also received a report with all their results and these can be found on the [website](#).

We compared results for each of the four NHS England regions and Wales. [Regional reports](#) and the [report for Wales](#) are also available.
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Royal College of Psychiatrists’ Centre for Quality Improvement

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