

# **National Audit of Dementia**

**Care in General Hospitals 2016-2017**

**An overview of the key messages for  
hospital managers and commissioners**



This report was produced by Chloë Snowden and Chloë Hood from the National Audit of Dementia Project Team. It was published in January 2018.

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## Contents

Background .....	2
Round 3 of NAD .....	3
Key messages from Round 3.....	4
Key message 1: Delirium recording requires improvement .....	5
Key message 2: Personal information to support better care must be accessible .....	6
Key message 3: Services must meet the nutritional needs of people with dementia .....	7
Key message 4: Championing dementia means supporting staff.....	8
Key message 5: Involve the person with dementia in decision making .....	9
Conclusion .....	10

# Background

The National Audit of Dementia (care in general hospitals) is commissioned by the Healthcare Quality Improvement Partnership on behalf of NHS England and the Welsh Government, as part of the National Clinical Audit Programme. It is managed by Royal College of Psychiatrists, in partnership with other organisations and charities.

The National Audit of Dementia (NAD) examines aspects of the care received by people with dementia in general hospitals in England and Wales.

## What is dementia?

Dementia is the term used to describe a range of symptoms caused by diseases which damage the brain, such as Alzheimer's disease, or a series of strokes. Symptoms vary extensively but may include memory loss and difficulties with thinking, language and problem solving, and changes in mood and behaviour<sup>1</sup>. For a person with dementia, these symptoms are severe enough to cause significant problems in daily life. Dementia is most prevalent in people over the age of 65 and the likelihood of developing dementia increases with age.

## Dementia in general hospitals

People with dementia are not generally admitted to hospital for their dementia. In Round 3 of the National Audit of Dementia, 50% of the primary causes for admission were either falls, hip fracture or dislocation, respiratory related or urinary infections.

Admission to hospital is exceptionally difficult for people with dementia. Illness or injury, loss of familiar surroundings and routine, and a busy task

centred environment can all worsen dementia symptoms and increase the risk of delirium.

The Alzheimer's Society cites figures obtained from Department of Health stating that people with dementia in hospital account for around 3.2 million bed days a year<sup>2</sup>.

Governments in both England and Wales have identified dementia care in hospitals as a priority for improvement.

## Previous Rounds of NAD

Two previous rounds of this audit have taken place, reporting in 2011 and 2013.

Round 2 of the audit found that some improvement had taken place in care processes, such as assessment and discharge planning. There was increased support for dementia in hospital through the introduction of senior clinical leads, dementia champions, and training provision. However, further improvement was needed.

<sup>1</sup> [https://www.alzheimers.org.uk/info/20007/types\\_of\\_dementia/1/what\\_is\\_dementia](https://www.alzheimers.org.uk/info/20007/types_of_dementia/1/what_is_dementia)

<sup>2</sup> [https://www.alzheimers.org.uk/download/downloads/id/2907/fix\\_dementia\\_care\\_-\\_hospitals.pdf](https://www.alzheimers.org.uk/download/downloads/id/2907/fix_dementia_care_-_hospitals.pdf)

## Round 3 of NAD

Round 3 of the National Audit of Dementia collected data between April and November 2016. One hundred and ninety-nine hospitals (98% of eligible hospitals) in England and Wales took part in the audit and were asked to complete four elements:

- A hospital level organisational checklist
- A retrospective casenote audit, with a minimum target of 50 sets of patient notes
- A survey of carer experience of quality of care
- A staff questionnaire about providing care and support to people with dementia.

In total, the audit received 199 organisational checklists, 10047 casenote submissions, 14416 staff questionnaires and 4664 carer questionnaires.

### This report

This is a Round 3 summary report for hospital managers and commissioners. It highlights the key areas of focus for general hospitals in England and Wales following the results of the audit. The [full report](#) for Round 3 contains further details on the audit methods, findings and recommendations.

Regional and individual hospital reports can also be found on the [audit website](#).

### Key messages and recommendations

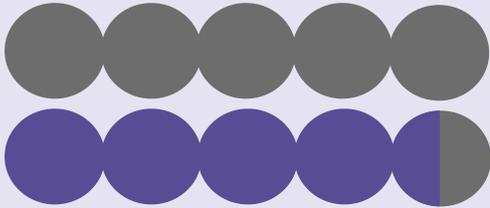
The national report identified five key messages and recommendations based on the findings of Round 3. These are the areas which the audit recommends hospitals should focus on as areas of immediate priority.

An overview of the five key messages can be found on the next page, and a more in-depth explanation of the key messages, and the associated key recommendations, follows.

# National Audit of Dementia

## Key messages from Round 3

### Delirium recording requires improvement



45% of patients with dementia had an initial screen for delirium

### Personal information to support better care must be available

In a spot check, half of patients with dementia who should have had a personal information document, had one in place



### Services must meet the nutritional needs of people with dementia



A quarter of hospital staff said the nutritional needs of people with dementia were met only sometimes, or not at all

### Championing dementia means supporting staff

One in two hospital staff said they feel supported by dementia specialist staff out of office hours



### Involve the person with dementia in decision making



Consent (or a best interest decision making process) was recorded in two thirds of referrals to a social worker, for a proposed change in residence

# Key message 1: Delirium recording requires improvement

## What is delirium?

Delirium is an “acute decline in mental functioning with confusion, over activity or underactivity, distress (hallucinations, paranoia). Usually caused by acute medical illness, surgery, or by medicines or medication withdrawal. Most patients recover, in a few days to a few weeks. Delirium is not the same as dementia, which is chronic and generally irreversible”<sup>3</sup>.

Delirium can affect over a quarter of older patients in hospital and may have long-lasting effects on cognition, as well as physical decline<sup>4</sup>. Delirium has been shown to increase length of stay<sup>5</sup> and is linked to number of falls<sup>6</sup> and premature death<sup>7</sup>.

You can find more information and resources about delirium on the [Scottish Delirium Association website](#).

## Delirium in Round 3 of NAD

In Round 3 of NAD, in more than half of casenotes of people with dementia, there was no recording of an initial screen or check for symptoms of delirium. Inconsistency in what is recorded and communicated may affect clinical care and thereby increase a person with dementia’s risk of developing delirium.

For more information on the data regarding delirium from Round 3 of NAD, please see the [National Report](#).

## NAD recommendations

**Medical and Nursing Directors** should:

- Ensure that hospitals have robust mechanisms in place for assessing delirium in people with dementia including:
  - At admission, a full clinical delirium assessment, whenever indicators of delirium are identified.
  - Cognitive tests administered on admission and again before discharge.
  - Delirium screening and assessment fully documented in the patient’s notes (regardless of the outcome).
  - Care offered in concordance with the delirium evidence-base recommendations when the assessment indicates symptoms of delirium.
  - Results recorded on the electronic discharge summary.
- Ensure staff receive training in delirium and its relationship to dementia, manifestations of pain, and behavioural and psychological symptoms of dementia.

## Comments from staff, carers or service users in NAD

*...[There] is a lack of awareness about delirium. My husband suffered from this... on admission... Fortunately, I recognised the symptoms, exactly the same had happened [before]. On that occasion, I had no knowledge of the condition and no-one explained it to me. It was only when I picked up a leaflet... I understood why he was talking in such a confused way - akin to paranoia - and why he was seeing things that were not there. This is an area... for improvement so staff and carers are fully aware of the condition and the reasons for it.*

Carer, Carer questionnaire

<sup>3</sup><https://docs.google.com/viewer?a=v&pid=sites&srcid=ZGVmYXVsdGRvbWFpbXZlY290dGlzaGRlbglyXVtYXNzb2NpYXRpb258Z3g6N2M2NTgxOTczOWFmZWQwOQ>

<sup>4</sup> <https://jamanetwork.com/journals/jamapsychiatry/article-abstract/2598162>

<sup>5</sup> <https://www.journalofhospitalmedicine.com/jhospmed/article/127572/delirium-superimposed-dementia>

<sup>6</sup> [http://www.psychosomaticsjournal.com/article/S0033-3182\(09\)70791-1/fulltext](http://www.psychosomaticsjournal.com/article/S0033-3182(09)70791-1/fulltext)

<sup>7</sup> <https://jamanetwork.com/journals/jama/article-abstract/186304?redirect=true>

## Key message 2: Personal information to support better care must be accessible

### What is a personal information document?

A personal information document contains key information about the care and communication needs of a person with dementia. There are different versions of the document (e.g. [This is Me](#)) but they are all intended to capture information such as preferred name, food likes and dislikes, factors which can cause distress and how these can be mitigated.

### Personal information documents in Round 3 of NAD

A ward spot check carried out during the audit looked for the document with key personal information about care needs and communication that should be completed for people with dementia. The spot check found that only half of patients who should have had a personal information document, had one in place.

Forty percent of staff said that they could not access personal information at least most of the time. Under half of carers said they thought staff were 'definitely' well informed about the person with dementia.

For more information on the data regarding personal information from Round 3 of NAD, please see the [National Report](#).

### NAD recommendations

**National Commissioners (Welsh Government, NHS England)** should propose a nationally backed monitoring programme aimed at embedding the collection, sharing and use of person centred information. This should include a clear expectation that once gathered, this information will follow the patient between providers, and this will be monitored.

**Ward Managers** should audit implementation/use of personal information collected to improve care for patients (e.g. This is Me or other locally developed document). The result of the audit should be fed back to the dementia champions/dementia lead and ward staff.

### Comments from staff, carers or service users in NAD

*No-one asked me about her needs... her behaviour, her dietary needs, personal care, and general agitation/capacity.*

Carer, carer questionnaire

*'This is Me' forms are vital in caring for our patients with dementia, however these are rarely completed.*

Healthcare assistant, staff questionnaire

*Given the 'This is Me' leaflet the afternoon before mum was discharged. Should have had this form on the first day, not the fifth day!*

Carer, carer questionnaire

## Key message 3: Services must meet the nutritional needs of people with dementia

### Nutritional needs of people with dementia

Catering services in hospitals should be able to provide for the needs of patients with dementia. People with dementia may not be able to eat full meals at regular times, may need finger food meal alternatives (food which can be eaten without cutlery) or snacks at any time of day, to ensure they are nourished.

Malnutrition is linked to many health outcomes – from the healing and development of pressure ulcers<sup>8</sup> to the development of hospital acquired infections<sup>9</sup>. Malnutrition in hospitals has also been linked to increased length of stay and cost<sup>10</sup>.

### Nutritional needs of people with dementia in Round 3 of NAD

In Round 3, less than 75% of staff said that they could obtain finger foods or snacks between meals for these patients.

Twenty-four percent of staff thought people with dementia had their nutritional needs met sometimes, or not met.

For more information on the data regarding the nutritional needs of people with dementia from Round 3 of NAD, please see the [National Report](#).

### NAD recommendations

#### **Clinical Commissioning Groups and Health Board commissioning services should**

ensure that tenders let by Trusts for new catering contracts always specify provision of finger foods for main meals and access to a range of snacks 24 hours a day.

**Medical and Nursing Directors should** promote the attendance of key carers to support care, but ensure that this is complementary to, and not instead of, care delivered by staff. The level of input by carers, and how carers feel about the level of input they have been asked to deliver should be monitored through carer feedback, complaints and PALS enquiries. Carer satisfaction should be seen as a marker of good care. Ward managers should be supported to ensure carers supporting patients should not be asked to leave at mealtimes/stopped from helping with meals (this excludes emergency and urgent care and treatment).

### Comments from staff, carers or service users in NAD

*I work nightshifts and no suitable food is left for patients overnight and we are often asked for late evening/night snacks from patients. It is not a good feeling to not be able to provide a snack for patients... I have often given food/drink of my own to patients in order to help.*

Healthcare assistant, staff questionnaire

*My mum was well looked after but could not eat the food provided so we had to bring our own food in, so she [could] have something to eat...*

Carer, carer questionnaire

<sup>8</sup> [http://www.nutritionjrn.com/article/S0899-9007\(10\)00054-7/fulltext](http://www.nutritionjrn.com/article/S0899-9007(10)00054-7/fulltext)

<sup>9</sup> <https://www.cambridge.org/core/journals/british-journal-of-nutrition/article/malnutrition-is-an-independent-factor-associated-with-nosocomial-infections/2C14D9A485B2E2596E6849CECD77D089>

<sup>10</sup> [http://www.clinicalnutritionjournal.com/article/S0261-5614\(02\)00215-7/fulltext](http://www.clinicalnutritionjournal.com/article/S0261-5614(02)00215-7/fulltext)

## Key message 4: Championing dementia means supporting staff

### Specialist staff for dementia in hospitals

Dementia champions are members of staff who have special responsibility to promote best practice in caring for people who have dementia and supporting staff in providing care.

Hospital staff may also access support in caring for people with dementia from specialist liaison mental health teams or care of the elderly teams.

### Staff support in Round 3 of NAD

To support staff to deliver better care, nearly all hospitals have created dementia champions at ward level.

Just under 70% of carers gave a high rating to care overall.

Staff said they needed more support, especially out of hours when less than a quarter of staff said they could access specialist support for dementia always or most of the time.

For more information on the data regarding supporting staff with dementia care from Round 3 of NAD, please see the [National Report](#).

### NAD recommendations

**The Chief Executive Officer should** ensure that there is a dementia champion available to support staff 24 hours per day, 7 days per week. This could be achieved through ensuring that people in roles such as Site Nurse Practitioners and Bed Managers have expertise in dementia care.

### Comments from staff, carers or service users in NAD

*I think nursing staff should receive more training and education of dementia or there should be more specialist nurses. They have Macmillan nurses for cancer patients, who do an excellent job, so why not have dementia nurses?*

Carer, carer questionnaire

*Knowing that someone understands me is important.*

Service user, member of a service user review panel

*[We need] more specialist advice about how to treat patients on hand and available, not just in office hours.*

Allied healthcare professional, staff questionnaire

## Key message 5: Involve the person with dementia in decision making

### Consent or a best interest decision making process

As their discharge date approaches, people with dementia often face discussions about whether their current residence is the most appropriate place for them to live. They may be referred to a social worker to discuss a possible change and the hospital should record their consent to this referral.

Where a patient lacks capacity, and a decision to refer has been taken in their best interests, this should be recorded.

### Consent or a best interest decision making process in Round 3 of NAD

In the audit, where a change in residence after discharge (e.g. from their own home to a care home) was proposed, just over one third of patients did not have their consent to begin this process recorded, or evidence that a best interests decision making process had taken place (in the case that they lacked capacity).

For more information on the data regarding involving the person with dementia in decision making from Round 3 of NAD, please see the [National Report](#).

### NAD recommendations

**The Safeguarding Lead should** ensure that staff are trained in the Mental Capacity Act, including consent, appropriate use of best interests decision making, the use of Lasting Power of Attorney and Advance Decision Making. Training should cover supportive communication with family members/carers on these topics.

### Comments from staff, carers or service users in NAD

*I was particularly unhappy about a meeting... to discuss the care plan... I asked if both I and my relative should come and he said, 'No, just you to begin with.' When I said I'd prefer to stay with my relative, I was told that the Psychiatrist wanted me to attend... The room had blinds on the windows but these weren't fully closed, and I soon became aware that my relative was outside, looking in. After a while he entered the room of his own accord and was clearly very angry and upset that we had all been talking about him behind his back.*

Carer, carer questionnaire

*[We need] better training, knowledge and support for staff around the principles of the Mental Capacity Act, supporting patients to make every day and complex decisions. Particularly taking into account, communication and cognitive needs that would affect support for decision-making.*

Allied healthcare professional, staff questionnaire

## Conclusion

This report contains a summary of the key findings and recommendations from Round 3 of the National Audit of Dementia. The key messages focus on the areas of priority for hospitals identified from the national dataset and thus show areas for improvement across England and Wales.

Participating hospitals also received individual local reports (found on the [audit website](#)) in order to identify and make changes key to that hospital.

The audit Project Team would encourage commissioners and hospital managers to implement the recommendations specifically aimed at commissioning and managing bodies. We also encourage you to note all the key recommendations, to understand how you can support and monitor their implementation.

Feedback from hospital staff, carers and service users in each round of audit has consistently underlined the necessity of a whole organisation approach, involving staff from all disciplines and seniority levels working together to bring the best possible care to people with dementia.

Dementia champions and other key staff are very important to dementia care but require support and engagement from all staff to see the implementation of key dementia strategies through to ward level.

*[We need] grassroots education of staff by ward and departmental management. Many schemes exist to improve the care of patients with dementia but getting ward staff to consistently implement these schemes is very difficult and this leads to a worse experience for some patients. This is about staff engagement wholesale, rather than anything one specialist nurse can do alone.*

Patient Experience team member, staff  
questionnaire

*I cannot imagine that dementia comes anywhere high on the list of priorities for any hospital. I do hope I find out it is different to this.*

Carer, member of a service user review panel

## Round 4 of the National Audit of Dementia

The next round of the National Audit of Dementia will be taking place from April 2018. Hospital audit leads have been contacted to ask them to register for the audit.

More details about Round 4 can be found on the [website](#).

Round 3 showed that engagement with the audit directly impacts data returns, particularly in relation to the numbers of carer and staff questionnaire returns. Audit leads will be provided with regular updates on their hospital submissions during the data collection period.

We would encourage commissioners and hospital managers to keep up to date with the timeline for the audit through regular contact with their audit lead.

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