

Dementia: support in health and social care

Quality standard

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This standard is based on NG97.

This standard should be read in conjunction with QS30, QS13, QS50, QS63, QS123 and QS164.

Introduction and overview

Introduction

January 2014. Following the [independent review of the use of the Liverpool Care Pathway \(LCP\) for the dying patient](#) and the subsequent announcement of the phasing out of the LCP, reference to the LCP has been removed from the health and social care professionals' audience description for statement 9.

Dementia is a progressive and largely irreversible clinical syndrome that is characterised by a widespread impairment of mental function. Although many people with dementia retain positive personality traits and personal attributes, as their condition progresses they can experience some or all of the following: memory loss, language impairment, disorientation, changes in personality, difficulties with activities of daily living, self-neglect, psychiatric symptoms (for example, apathy, depression or psychosis) and out-of-character behaviour (for example, aggression, sleep disturbance or disinhibited sexual behaviour, although the latter is not typically the presenting feature of dementia).

Dementia is associated with complex needs and, especially in the later stages, high levels of dependency and morbidity. These care needs often challenge the skills and capacity of carers and services. As the condition progresses, people with dementia can present carers and social care staff with complex problems including aggressive behaviour, restlessness and wandering, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures. The impact of dementia on an individual may be compounded by personal circumstances such as changes in financial status and accommodation, or bereavement. This quality standard provides clinicians, managers and service users with a description of what a high-quality dementia service should look like.

This quality standard covers care provided by health and social care staff in direct contact with people with dementia in hospital, community, home-based, group care, residential or specialist care settings. It should be read alongside the NICE quality standard for [dementia: independence and](#)

wellbeing, which applies to all social care settings and services working with and caring for people with dementia. The NICE Pathway on dementia presents the information from both quality standards in an integrated format.

Overview

The quality standard for dementia requires that dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.

List of statements

Statement 1 People with dementia receive care from staff appropriately trained in dementia care.

Statement 2 People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Statement 3 People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

Statement 4 People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

Statement 5 People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities for Care.

Statement 6 Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

Statement 7 People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

Statement 8 People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Statement 9 People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Statement 10 Carers of people with dementia have access to a comprehensive range of respite/ short-break services that meet the needs of both the carer and the person with dementia.

In addition, quality standards that should also be considered when commissioning and providing a high-quality dementia service are listed in related NICE quality standards.

Quality statement 1: Appropriately trained staff

Quality statement

People with dementia receive care from staff appropriately trained in dementia care.

Quality measure

Structure: Evidence of local arrangements to provide and maintain up to date dementia training for staff.

Process: Proportion of staff working with people with dementia who have dementia care training.

Numerator – the number of staff who are trained in dementia care.

Denominator – the number of staff working with people with dementia.

What the quality statement means for each audience

Service providers ensure that all health and social care workers are appropriately trained in dementia care according to their roles and responsibilities.

Health and social care professionals who work with people with dementia ensure they receive training in dementia care consistent with their roles and responsibilities.

Commissioners ensure service providers have arrangements for training health and social care professionals in dementia care.

People with dementia can expect that the health and social care professionals who care for them will have dementia care training.

Data source

Structure: Local data collection. Acute Trusts can collect data on dementia awareness training using the [National Audit of Dementia](#) organisational checklist, section 7.

Process: Local data collection.

Quality statement 2: Memory assessment services

Quality statement

People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Quality measure

Structure: Evidence that memory assessment services specialising in the diagnosis and initial management of dementia are the single point of referral for people with a possible diagnosis of dementia.

Process: Proportion of people with suspected dementia who are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Numerator – the number of people who are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

Denominator – the number of people with suspected dementia.

What the quality statement means for each audience

Service providers ensure they offer a full range of services to aid diagnosis and initial management of dementia.

Health and social care professionals working with those with a possible diagnosis of dementia are aware of the process by which referrals can be made to the local memory assessment service.

Commissioners ensure all referrers can access memory assessment services for people with a possible diagnosis of dementia.

People receiving a possible diagnosis of dementia can expect to be referred to a memory assessment service.

Data source

Structure: Local data collection.

Process: Local data collection.

Quality statement 3: Written and verbal information

Quality statement

People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

Quality measure

Structure: Evidence of local arrangements to ensure written information on dementia is available to staff.

Process: Proportion of people newly diagnosed with dementia receiving written and verbal information about their condition, treatment and the support options in their local area.

Numerator – the number of people receiving written and verbal information about their condition, treatment and the support options in the local area.

Denominator – the number of people newly diagnosed with dementia.

What the quality statement means for each audience

Service providers ensure that written information about dementia, treatment and local area support options is available to staff.

Health and social care professionals provide written and verbal information about dementia, treatment and local area support options once a diagnosis of dementia is established.

Commissioners ensure that services make available written information about dementia, treatment and local area support options.

People newly diagnosed with dementia can expect to be provided with written and verbal information about their condition, treatment and the support options in their local area.

Definitions

Written information for patients can be found in the Department of Health's [Who cares?](#) booklet.

Data source

Structure: Local data collection. Acute Trusts, Primary Care Trusts and Mental Health Trusts can demonstrate processes for developing written information via [NHS Litigation Authority Risk Management Standards 4, criterion 2](#).

Process: Local data collection.

Quality statement 4: Assessment and personalised care plan

Quality statement

People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care, that identifies a named care coordinator and addresses their individual needs.

Quality measure

Structure: Evidence of local arrangements to ensure services are tailored to an individual's needs.

Process:

a) Proportion of people with dementia whose individual needs are assessed and whose care plan states how those needs will be addressed.

Numerator – the number of people with an assessment of individual needs and a care plan addressing identified needs.

Denominator – the number of people with dementia

b) Proportion of people with a named health or social care coordinator.

Numerator – the number of people with a named health or social care coordinator.

Denominator – the number of people with dementia.

What the quality statement means for each audience

Service providers ensure that protocols are in place to ensure that personalised care plans identify named care coordinator and address the individual needs of people with dementia.

Health and social care professionals ensure that personalised care plans identify a named care coordinator and address the individual needs of the person with dementia.

Commissioners ensure that services are commissioned that tailor interventions to the individual needs of a person with dementia.

People with dementia can expect to receive a care plan that identifies a named care coordinator and addresses their individual needs.

Definitions

'Individual needs' arise from:

- Diversity, including gender, ethnicity, age (younger or older), religion and personal care.
- Ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities.
- The life story and preferences of people with dementia and their carer/s (where possible) including diet, sexuality and religion.
- Maintaining independence.
- Information needs.

'Care coordinator/health and social care coordinator': These terms refer to a professional who has lead responsibility for a person's treatment and care. It is not suggested that all people with dementia will supported by a CPA care coordinator.

Data source

Structure: Local data collection.

Process:

a) Local data collection.

b) Local data collection.

Quality statement 5: Decision making

Quality statement

People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of:

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities for Care.

Quality measure

Structure: Evidence of local protocols on the discussion of advance decision making.

Process: Proportion of people with dementia, while they have capacity, and their carer/s, who are given the opportunity to discuss with health and social care professionals about the use of:

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities for Care.

Numerator – the number of people who are given the opportunity to discuss advance decision making.

Denominator – the number of people with dementia.

Numerator – the number of carers who are given the opportunity to discuss advance decision making.

Denominator – the number of carers of people with dementia.

What the quality statement means for each audience

Service providers ensure staff are appropriately trained to provide information on advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and Preferred Priorities for Care.

Health and social care professionals offer the person with dementia, whilst they have capacity, the opportunity to discuss and make decisions together with their carer/s about the use of:

- advance statements
- advance decisions to refuse treatment
- Lasting Power of Attorney
- Preferred Priorities for Care.

Commissioners ensure that local arrangements for assessment and care planning specifically include advance decision making.

People with dementia and their carers can expect the opportunity to discuss and make a decision on the use of advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and Preferred Priorities for Care.

Data source

Structure: Local data collection.

Process: Local data collection.

Quality statement 6: Emotional, psychological and social needs of carers

Quality statement

Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

Quality measure

Structure:

- Evidence that those carrying out a carers' assessment identify any emotional and psychological needs and the social impact on the carer and offer the carer psychological therapy, including cognitive behavioural therapy (CBT), if clinically appropriate.
- Evidence that this is an ongoing process and includes any period after the person with dementia has entered residential care.
- Evidence that care plans for carers of people with dementia involve a range of tailored interventions, which consist of multiple components including:
 - individual or group psychoeducation
 - peer-support groups with other carers, tailored to the needs of individuals depending on the stage of dementia of the person being cared for and other characteristics.

Process:

a) Proportion of carers of people with dementia who are offered an assessment of their needs.

Numerator – the number of carers offered an assessment of their needs.

Denominator – the number of carers of people with dementia.

b) Proportion of carers of people with dementia receiving interventions tailored to their needs.

Numerator – the number of carers receiving interventions tailored to their needs

Denominator – the number of carers of people with dementia who have an agreed care plan.

What the quality statement means for each audience

Service providers ensure that carers of people with dementia are offered an assessment of needs and receive tailored interventions to address any identified.

Health and social care professionals ensure that carers accepting an assessment of their needs receive a care plan containing a range of tailored interventions including:

- psychological therapy including CBT
- psychoeducational programmes
- peer support.

Commissioners ensure services offer a range of tailored interventions.

Carers of people with dementia can expect to be offered an assessment of their needs and tailored interventions to address any needs that are identified.

Data source

Structure: Local data collection.

Process: Local data collection. Contained within the [National Audit of Dementia](#).

Quality statement 7: Non-cognitive symptoms and behaviour that challenges

Quality statement

People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.

Quality measure

Structure:

- a) Evidence that people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity.
- b) Evidence that individually tailored care plans, that help carers and staff address the behaviour that challenges, are recorded in the notes and reviewed regularly.

Process:

- a) Proportion of people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, who receive an assessment to establish likely factors that may generate, aggravate or improve such distress or behaviour.

Numerator – the number of people who receive an assessment.

Denominator – the number of people with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges.

- b) Proportion of people with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, with an individualised care plan identifying actions to address the distress or behaviour.

Numerator – the number of people with an individualised care plan identifying actions to address the distress or behaviour.

Denominator – the number of people with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges.

c) Proportion of people with dementia with mild-to-moderate non-cognitive symptoms who are prescribed anti-psychotic medication. (Goal to be 0% reflecting the [Department of Health report on the prescribing of anti-psychotic drugs to people with dementia](#) and its aim to reduce the use of anti-psychotic medication for people with dementia.)

Numerator – the number of people prescribed anti-psychotic medication.

Denominator – the number of people with dementia with mild-to-moderate non-cognitive symptoms.

What the quality statement means for each audience

Service providers ensure that all people with dementia who develop non-cognitive symptoms that cause significant distress, or who develop behaviour that challenges, are given a comprehensive assessment.

Health and social care professionals working with people with dementia who develop non-cognitive symptoms carry out a comprehensive assessment. A behavioural and functional analysis should be conducted by health and social care professionals with specific skills, in conjunction with carers and care workers, and an individually tailored care plan should be developed to address the issues.

Commissioners ensure local service providers are adequately resourced and trained to undertake comprehensive assessment and management of people with non-cognitive symptoms of dementia.

People with dementia who develop non-cognitive symptoms that cause them significant distress or who develop behaviour that challenges can expect to be offered a comprehensive assessment at an early stage.

Definitions

The assessment must include:

- the person's physical health
- depression

- possible undetected pain or discomfort
- side effects of medication
- individual biography, including religious beliefs and spiritual and cultural identity
- psychosocial factors
- physical environmental factors
- behavioural and functional analysis conducted by professionals with specific skills, in conjunction with carers and care workers.

Data source

Structure: Local data collection. Contained within the [National Audit of Dementia](#).

Process:

a) and b) Local data collection.

c) Local data collection. Acute Trusts can collect data on the main recorded reason for any prescription of antipsychotic medication using the [National Audit of Dementia](#) case note audit, section 2 (however, the audit is not specific to people with mild-to-moderate non-cognitive symptoms).

Quality statement 8: Liaison services

Quality statement

People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Quality measure

Structure: Evidence of local arrangements to provide a liaison service specialising in the diagnosis and management of dementia and older people's mental health.

Process: Proportion of people with suspected or known dementia using acute and general hospital facilities that are assessed by a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Numerator – the number of people who are assessed by a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

Denominator – the number of people with suspected or known dementia who are admitted to acute or general hospital inpatient services or attending emergency departments.

What the quality statement means for each audience

Service providers ensure that a liaison service specialising in dementia and older people's mental health is available in acute and general hospital settings to assess inpatients and emergency department attendances with suspected or confirmed dementia.

Healthcare professionals working in acute and general hospital settings ensure they can access a liaison team that specialises in the diagnosis and management of dementia and older people's mental health.

Commissioners ensure provision of a liaison service specialising in dementia and older people's mental health to work across acute and general hospital settings to assess people with suspected or known dementia.

People with suspected or known dementia admitted to acute and general hospital settings or

attending emergency departments can expect, if clinically appropriate, to receive an assessment by a liaison service specialising in dementia and older people's mental health.

Definitions

Local commissioning arrangements should decide the activity levels for the liaison service.

Data source

Structure: Local data collection. Acute Trusts can collect data on the composition of liaison teams using the [National Audit of Dementia](#) organisational checklist, section 9.

Process: Local data collection. Acute Trusts can collect data on referrals to liaison teams using the [National Audit of Dementia](#) case note audit, section 4. Also contained within NHS England's [Dementia Assessment and Referral statistics](#).

Quality statement 9: Palliative care needs

January 2014. Following the [independent review of the use of the Liverpool Care Pathway \(LCP\) for the dying patient](#) and the subsequent announcement of the phasing out of the LCP, reference to the LCP has been removed from the health and social care professionals' audience description for this statement.

Quality statement

People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

Quality measure

Structure: Evidence of local arrangements for primary care teams to assess the palliative care needs of people in the later stages of dementia.

Process: Proportion of people in the later stages of dementia whose palliative care needs are assessed by primary care teams and the resulting information is communicated within the team and with other health and social care staff.

Numerator – the number of people whose palliative care needs are assessed by a primary care team and communicated within the team and with other health and social care staff.

Denominator – the number of people in the later stages of dementia.

What the quality statement means for each audience

Service providers ensure that all people in the later stages of dementia have their palliative care needs assessed by primary care teams and that the needs are communicated to other health and social care staff.

Health and social care professionals ensure that people who are in the later stages of dementia have their palliative care needs met in accordance with the DH's [End of Life Care Strategy](#). This includes use of appropriate tools and pathways including:

- [Preferred priorities for care](#)

- Gold Standards Framework.

Commissioners ensure primary care teams are resourced and trained to provide palliative care for people with dementia.

People in the later stages of dementia can expect their palliative care needs to be assessed by their primary care team and for the results to be communicated to relevant staff.

Definitions

Later stages of dementia can be defined as those with an established diagnosis of moderate or more severe dementia.

Data source

Structure: Local data collection

Process: Local data collection

Quality statement 10: Respite services for carers

Quality statement

Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

Quality measure

Structure: Evidence that health and social care managers ensure that carers of people with dementia have access to a comprehensive range of respite/short-break services which meet the needs of both the carer and the person with dementia.

Process: Proportion of carers of people with dementia who access respite/short-break services when required.

Numerator – the number of carers accessing respite/short-break services.

Denominator – the number of carers of people with dementia requesting respite/short-break services.

What the quality statement means for each audience

Service providers ensure that information is available to health and social care staff on the range of respite/short-break services available to carers of people with dementia.

Health and social care professionals ensure that carers of people with dementia are aware of the options available to them locally for respite/short-break services, and that access to such services is facilitated when needed.

Commissioners ensure a comprehensive range of local respite/short-break services are accessible and meet the needs of both carers and people with dementia.

Carers of people with dementia can expect to have access to a range of respite/short-break services which meet their needs.

Data source

Structure: Local data collection.

Process: Local data collection.

Using the quality standard

It is important that the quality standard is considered alongside current policy and guidance documents listed in the [development sources](#) section.

[Information for the public](#) about the quality standard is also available.

Quality measures and national indicators

The quality measures accompanying the quality standard aim to improve the structure, process and outcomes of health and social care. They are not a new set of targets or mandatory indicators for performance management.

Expected levels of achievement for quality measures are not specified. As quality standards are intended to drive up the quality of care, achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, we recognise that this may not always be appropriate in practice taking account of patient safety, patient choice and clinical judgement and therefore desired levels of achievement should be defined locally.

For further information, including guidance on using quality measures, please see [how to use quality standards](#).

Diversity, equality and language

During the development of this quality standard, equality issues were considered.

Good communication between health and social care professionals and people with dementia is essential. Treatment and care, and the information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, sensory or learning disabilities, and to people who do not speak or read English. People with dementia should have access to an interpreter or advocate if needed.

Development sources

Evidence sources

The document below contains clinical guideline recommendations or other recommendations that were used by the TEG to develop the quality standard statements and measures.

NICE (2018) [Dementia: assessment, management and support for people living with dementia and their carers](#). NICE guideline NG97

Policy context

It is important that the quality standard is considered alongside current policy documents, including:

- National Audit Office (2010) [Improving dementia services in England: an Interim report](#)
- Department of Health (2009) [The use of antipsychotic medication for people with dementia: Time for action](#)
- Department of Health (2009) [Living well with dementia: a national dementia strategy](#)
- National Audit Office (2007) [Improving services and support for people with dementia](#)

Related NICE quality standards

- [Dementia: independence and wellbeing \(2013\)](#) NICE quality standard 30
- [Patient experience in adult NHS services \(2012\)](#) NICE quality standard 15
- [End of life care for adults \(2011, updated 2017\)](#) NICE quality standard 13

The Topic Expert Group and NICE project team

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Update information

January 2014: Statement 9 was updated to remove mention of the Liverpool Care Pathway for the dying from the health and social care professionals' audience description for this statement.

Minor changes since publication

June 2018: Changes have been made to align this quality standard with the updated NICE guideline on [dementia](#). The evidence source has been updated.

November 2016: Data sources updated for statements 6, 7 and 8.

About this quality standard

NICE quality standards are a set of specific, concise statements and associated measures. They set out aspirational, but achievable, markers of high-quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from the best available evidence such as NICE guidance and other evidence sources accredited by NHS Evidence, they are developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.

The methods and processes for developing NICE quality standards are described in the [process guide](#).

This quality standard has been incorporated into the NICE Pathway on [dementia](#).

We have produced a [summary for patients and carers](#).

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Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Royal College of Psychiatrists](#)
- [Social Care Institute for Excellence](#)
- [Alzheimer's Society](#)