

# Dementia

Quality standard

Published: 28 June 2019

[www.nice.org.uk/guidance/qs184](https://www.nice.org.uk/guidance/qs184)

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This standard replaces QS1 and QS30.

This standard is based on NG97 and NG16.

This standard should be read in conjunction with QS13, QS50, QS63, QS85, QS123, QS132, QS136, QS137, QS144, QS153, QS171, QS15, QS14, QS182 and QS185.

## Quality statements

**Statement 1** People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes. [new 2019]

**Statement 2** People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated. [2010, updated 2019]

**Statement 3** People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review. [2010, updated 2019]

**Statement 4** People with dementia have a single named practitioner to coordinate their care. [2010, updated 2019]

**Statement 5** People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences. [2013, updated 2019]

**Statement 6** People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. [2010, updated 2019]

**Statement 7** Carers of people with dementia are offered education and skills training. [2010, updated 2019]

In 2019, this quality standard was updated to focus on a small number of priority areas for quality improvement. Statements included in 2010 and 2013 may have been updated [2010 or 2013, updated 2019] or replaced [new 2019]. For more information, see [update information](#).

Statements 1, 3, 9 and 10 from the [2010 quality standard for dementia: support in health and social care](#) and statements 1, 2, 3, 5, 6, 7, 8, 9 and 10 from the [2013 quality standard for dementia](#):

independence and wellbeing are still supported by the evidence. These may be useful at a local level and are available as pdfs on the history tab.

NICE has developed guidance and a quality standard on patient experience in adult NHS services, service user experience in adult mental health services and people's experience using adult social care services (see the NICE Pathways on patient experience in adult NHS services, service user experience in adult mental health services and people's experience in adult social care services), which should be considered alongside these quality statements.

Other quality standards that should be considered when commissioning or providing dementia services include:

- Medicines management for people receiving social care in the community (2018) NICE quality standard 171
- Multimorbidity (2017) NICE quality standard 153
- Care of dying adults in the last days of life (2017) NICE quality standard 144
- Mental wellbeing and independence for older people (2016) NICE quality standard 137
- Transition between inpatient hospital settings and community or care home settings for adults with social care needs (2016) NICE quality standard 136
- Social care for older people with multiple long-term conditions (2016) NICE quality standard 132
- Home care for older people (2016) NICE quality standard 123
- Medicines management in care homes (2015) NICE quality standard 85
- Delirium in adults (2014) NICE quality standard 63
- Mental wellbeing of older people in care homes (2013) NICE quality standard 50
- End of life care for adults (2013) NICE quality standard 13

A full list of NICE quality standards is available from the quality standards topic library.

## Quality statement 1: Raising awareness – health promotion interventions

### *Quality statement*

People accessing behaviour change interventions and programmes in mid-life are advised that the risk of developing dementia can be reduced by making lifestyle changes. [new 2019]

### *Rationale*

There is limited awareness among both the public and practitioners that the risk of developing some types of dementia can be reduced, or the onset or progression delayed, through lifestyle changes. Making this clear in interventions and programmes that promote behaviour change, such as NHS Health Checks and stop smoking services, should encourage changes in behaviour in mid-life, which could lead to fewer people developing dementia in later life.

### *Quality measures*

#### Structure

a) Evidence that service specifications for behaviour change interventions and programmes include actions to raise awareness of lifestyle changes that could reduce the risk of developing dementia.

**Data source:** Local data collection, for example, local service specifications.

b) Evidence that training for practitioners delivering behaviour change interventions and programmes includes how to advise and support people to reduce the risk of developing dementia.

**Data source:** Local data collection, for example, local service specifications.

c) Evidence that information about the link between unhealthy behaviours and the risk of developing dementia is included in local health promotion materials.

**Data source:** Local data collection, for example, local health promotion leaflets or websites.

#### Process

Proportion of people attending behaviour change interventions and programmes in mid-life who are advised that the risk of developing dementia can be reduced by making lifestyle changes.

**Numerator** –the number in the denominator who are advised that the risk of developing dementia can be reduced by making lifestyle changes.

**Denominator** – the number of people attending behaviour change interventions and programmes in mid-life.

**Data source:** Local data collection, for example, local audit of patient records.

## Outcomes

a) Public awareness of the link between dementia and lifestyle.

**Data source:** Local data collection, for example, public surveys.

b) Uptake of healthy lifestyle choices.

**Data source:** Local data collection, for example, public surveys. Public Health England's [Public Health Outcomes Framework data](#) includes data on portions of fruit and vegetables consumed, physical activity, smoking prevalence, alcohol-related admissions and social isolation of adults using social care. Public Health England also has [national profiles](#) on physical activity, alcohol and tobacco control.

## *What the quality statement means for different audiences*

**Service providers** (stop smoking services, leisure services, NHS Health Checks and other health and wellbeing service providers) ensure that staff delivering behaviour change interventions and programmes are aware of lifestyle changes that can reduce the risk of developing dementia, and offer advice on reducing this risk.

**Health and public health practitioners** (such as health improvement practitioners, health trainers, GPs, nurses, pharmacists and stop smoking advisers) are aware of the lifestyle changes that can reduce the risk of developing dementia and offer advice on reducing this risk.

**Commissioners** (such as clinical commissioning groups and local authorities) ensure that service specifications for behaviour change interventions and programmes include the lifestyle changes that can reduce the risk of developing dementia and the actions needed to raise awareness of these. They ensure that services delivering these interventions and programmes offer advice on reducing the risk of dementia.



People having NHS Health Checks or taking part in health and wellbeing programmes in mid-life are told about lifestyle changes they can make to reduce their risk of developing dementia.

### *Source guidance*

Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset (2015)  
NICE guideline NG16, recommendations 2, 4 and 9

### *Definitions of terms used in this quality statement*

#### **Mid-life**

Adults aged 40 to 64 years. Adults aged 39 years or under from disadvantaged populations may also be considered (this group is at increased risk of ill health and more likely to develop multiple morbidities).

[Adapted from NICE's guideline on dementia, disability and frailty in later life, What is this guideline about?]

#### **Lifestyle changes**

Behaviours such as smoking, lack of physical activity, unhealthy diet, alcohol consumption, being overweight or obese, and loneliness that can be changed to reduce the risk of developing dementia.

[NICE's guideline on dementia, disability and frailty in later life, recommendation 3]

### *Equality and diversity considerations*

People should be provided with information about the risk factors for dementia that they can easily read and understand themselves, or with support. Information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate.

## Quality statement 2: Diagnosis

### *Quality statement*

People with suspected dementia are referred to a specialist dementia diagnostic service if reversible causes of cognitive decline have been investigated. [2010, updated 2019]

### *Rationale*

Referral to dementia specialist diagnostic services ensures that diagnosis is timely and accurate, and dementia subtypes, such as Alzheimer's disease and dementia with Lewy bodies, can be identified. It also means that people can access support and treatment sooner. The benefits of a timely diagnosis include the person and their family and carers knowing what to expect so that they can consider future mental capacity and make plans early (advance care planning).

### *Quality measures*

#### **Structure**

Evidence of local referral criteria and pathways to ensure that people with suspected dementia are referred to a specialist dementia diagnostic service.

**Data source:** Local data collection, for example, local commissioning agreements and service specifications.

#### **Process**

Proportion of people with dementia who have a record of attending a specialist dementia diagnostic service up to 12 months before entering on to the GP practice register.

Numerator – the number in the denominator who were referred to a specialist dementia diagnostic service up to 12 months before entering on to the GP practice register.

Denominator – the number of people with dementia on the GP practice register.

**Data source:** Local data collection. An indicator was piloted and shown to be feasible by the NICE indicator programme. See [NICE indicator NM65](#).

## Outcome

Self-reported or carer-reported quality of life of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia. The [Dementia Quality of Life Measure \(DEMQOL\)](#) is a patient-reported outcome measure to enable the assessment of health-related quality of life of people with dementia.

### *What the quality statement means for different audiences*

**Service providers** (general practices, secondary care services, memory clinics, tertiary referral clinics, neurology clinics and geriatric medicine clinics) ensure that systems are in place to investigate reversible causes of cognitive decline. Specialist dementia diagnostic services and referral pathways should be in place so that people with suspected dementia can be referred after reversible causes have been investigated.

**Healthcare professionals** (such as GPs, neurologists and geriatricians) investigate reversible causes of cognitive decline, such as delirium, depression, sensory impairment (such as sight or hearing loss) or cognitive impairment from medicines associated with increased anticholinergic burden. If dementia is still suspected, they discuss referral with the person with suspected dementia, and refer them to a specialist dementia diagnostic service if the person agrees.

**Commissioners** (clinical commissioning groups and NHS England) ensure that they commission services that have referral pathways to a specialist dementia diagnostic service for people with suspected dementia and no reversible causes of cognitive decline.

**People with symptoms of dementia** have checks to see if something else is causing their symptoms. If dementia is still suspected, they have a discussion with the doctor about referral and, if they agree to it, they are referred to a specialist service for tests to find out whether they have dementia and, if so, what type they have.

**Family members and carers of people with suspected dementia** are involved in checks to see if something else is causing the person's symptoms, and in discussions about referral as appropriate. Their involvement might be needed if, for example, the person with symptoms of dementia lacks mental capacity or needs support in identifying their symptoms.

## *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.2.6

## *Definitions of terms used in this quality statement*

### **Suspected dementia**

Dementia that is suspected after reversible causes of cognitive decline (including delirium, depression, sensory impairment [such as sight or hearing loss] or cognitive impairment from medicines associated with increased anticholinergic burden) have been investigated.

[NICE's guideline on [dementia](#), recommendation 1.2.6]

### **Referred to a specialist dementia diagnostic service**

A specialist dementia diagnostic service might be a memory clinic or community old age psychiatry service. A referral to a diagnostic service does not have to involve a clinic appointment. People can be seen in community settings (such as their home or a care home), or advice can be provided to the referrer without a formal appointment being made. The key is to ensure that dementia specialists are involved, both for advice on diagnosis and to ensure appropriate access to support and treatment after diagnosis. Specialists are those with the appropriate knowledge and skills, and include secondary care medical specialists (for example, psychiatrists, geriatricians and neurologists) and other healthcare professionals (for example, GPs, nurse consultants and advanced nurse practitioners) with specialist expertise in assessing and diagnosing dementia.

[NICE's guideline on [dementia](#), recommendation 1.2.6 and terms used in this guideline]

## *Equality and diversity considerations*

People with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating. Healthcare professionals caring for people with dementia should establish the person's cognitive status, and whether they have any speech, language or other communication needs; they should also establish a person's current level of understanding and whether they would like a person important to them to be present when discussing symptoms and referral. All information provided should be accessible, as far as possible, to people with cognitive problems; people receiving information should have access to an interpreter or advocate if needed.

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, other ways of communicating (for example, visual aids or simplified text) should be used.

## Quality statement 3: Advance care planning

### *Quality statement*

People with dementia are given the opportunity to discuss advance care planning at diagnosis and at each health and social care review. [2010, updated 2019]

### *Rationale*

As dementia is a progressive condition, it is important for people to be able to make decisions about their future care early on, before they find it difficult to communicate or they lack the capacity to do so. This is known as advance care planning. It is important that there are opportunities to review and change the plan as the dementia progresses and if the preferences or needs of the person change. Having an advance care plan ensures that the person with dementia can receive treatment and care according to their preferences, even when they can no longer express them.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with dementia and people involved in their care have early and ongoing opportunities to discuss advance care planning.

**Data source:** Local data collection, for example, from local protocols.

#### **Process**

a) Proportion of people with dementia who are given information about advance care planning at diagnosis.

Numerator – the number in the denominator who were given information about advance care planning at diagnosis.

Denominator – the number of people with a new diagnosis of dementia.

**Data source:** Local data collection, for example, local audit of patient records.

b) Proportion of people with dementia having a health or social care review who have a documented discussion about advance care planning.

Numerator – the number in the denominator who have a documented discussion about advance care planning at their health or social care review.

Denominator – the number of people with dementia.

*Data source:* Local data collection, for example, local audit of patient records.

## Outcomes

a) Proportion of people with dementia who feel encouraged to make decisions about their future care.

Numerator – the number in the denominator who feel encouraged to make decisions about their future care.

Denominator – the number of people with dementia.

*Data source:* Local data collection, for example, a survey of people with dementia.

b) Proportion of people with dementia who are aware they can update their advance care plan at each care review.

Numerator – the number in the denominator who are aware they can update their advance care plan at each care review.

Denominator – the number of people with dementia.

*Data source:* Local data collection, for example, a survey of people with dementia.

## *What the quality statement means for different audiences*

**Service providers** (such as memory clinics, community old age psychiatry services, local authorities, neurology clinics, geriatric medicine clinics, community care providers or general practices) ensure that systems are in place for people with dementia and people involved in their care to have early and ongoing opportunities to discuss advance care planning.

**Health and social care professionals** (such as occupational therapists, psychiatrists, clinical psychologists, geriatricians, neurologists, GPs, nurse consultants, advanced nurse practitioners,

social workers and palliative care teams) give people with dementia and people involved in their care early and ongoing opportunities to discuss advance care planning.

**Commissioners** (such as local authorities, clinical commissioning groups and NHS England) ensure that they commission services that give people with dementia and people involved in their care early and ongoing opportunities to discuss advance care planning.

**People with dementia and people involved in their care** are supported to plan ahead and make decisions about future care when dementia is diagnosed and every time they have a care review.

### *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.1.12 and 1.1.13

### *Definitions of terms used in this quality statement*

#### **The opportunity to discuss advance care planning**

An opportunity for discussion about:

- the benefits of planning ahead
- lasting power of attorney (for decisions about health, welfare, property and financial affairs)
- an advance statement about their wishes, preferences, beliefs and values regarding their future care
- advance decisions to refuse treatment
- their preferences for place of care and place of death
- any cultural or religious preferences or practices.

This might involve giving information, providing contact details for when the person is ready to have a discussion, or having the discussion at that time, if the person is ready. Opportunities should be given to review and change any advance statements and decisions made at each care review.

[Expert opinion and NICE's guideline on [dementia](#), recommendations 1.1.12 and 1.1.13]



## *Equality and diversity considerations*

People with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare professionals caring for people with dementia should establish the person's cognitive status, and whether they have any speech, language or other communication needs. They should also establish the person's current level of understanding; and whether they would like a person important to them to be present when discussing preferences about their care. All information provided should be accessible, as far as possible, to people with cognitive problems; people receiving information should have access to an interpreter or advocate if needed.

## Quality statement 4: Coordinating care

### *Quality statement*

People with dementia have a single named practitioner to coordinate their care. [2010, updated 2019]

### *Rationale*

Dementia is a progressive condition with symptoms and care and support needs that change over time. People with dementia often have other long-term conditions, such as cardiovascular disease, diabetes, hearing loss and visual impairment, and many different practitioners might be involved in supporting their health and social care needs. To ensure that people with dementia experience person-centred care, it is important that there is a person responsible for supporting them through the disease course. The type of support needed will depend on the stage of dementia. During the earlier stages, this might be signposting to different services and support, whereas later it might be coordinating all aspects of their health and social care. The person with dementia can also develop and review a care and support plan with their named person.

### *Quality measures*

#### **Structure**

a) Evidence of local arrangements to ensure that people with dementia have a single named health or social care practitioner to coordinate their care.

**Data source:** Local data collection, for example, service specifications.

b) Evidence of local agreement of the role and functions of the named practitioner.

**Data source:** Local data collection, for example, service specifications and job descriptions.

#### **Process**

a) Proportion of people with dementia who have a named practitioner responsible for coordinating their care.

**Numerator** – the number in the denominator who have a named practitioner responsible for coordinating their care.

Denominator – the number of people with dementia.

**Data source:** Local data collection. An indicator was piloted and shown to be feasible by the NICE indicator programme. See [NICE indicator NM64](#).

b) Proportion of people with dementia who have a care and support plan.

Numerator – the number in the denominator who have a care and support plan.

Denominator – the number of people with dementia.

**Data source:** Local data collection, for example, local audit of patient records.

## Outcomes

a) Self-reported or carer-reported quality of life of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia. The [Dementia Quality of Life Measure \(DEMQOL\)](#) is a patient-reported outcome measure to enable the assessment of health-related quality of life of people with dementia.

b) Carer-reported quality of life of carers of people with dementia.

**Data source:** Local data collection, for example, a survey of carers of people with dementia. The Public Health England [Dementia Profile](#) includes data on carer-reported quality-of-life score for people caring for someone with dementia.

## *What the quality statement means for different audiences*

**Service providers** (such as dementia adviser services, local authorities, general practices, memory clinics, community old age psychiatry services and community care providers) ensure that systems are in place to identify and assign a single named practitioner to coordinate care for a person with dementia.

**Health or social care practitioners** (such as GPs, community psychiatric nurses, community matrons, psychologists, dementia advisers, occupational therapists or social workers) who are responsible for coordinating health and social care for a person with dementia get to know the person and their needs and preferences, and develop and review a care and support plan to ensure

that services and care are delivered in a coordinated and timely manner.

**Commissioners** (such as local authorities, clinical commissioning groups and NHS England) ensure that they commission services in which people with dementia are assigned a single named practitioner to coordinate their care. Commissioners make sure there is local agreement on the role and responsibilities of the person coordinating care.

**People with dementia** are told who in their care team has been chosen to coordinate their care and be their contact. They are given clear and up-to-date contact details for that person. The contact should keep the person and their family and carers at the centre of all decisions.

### *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.3.1

### *Definitions of terms used in this quality statement*

#### **Named practitioner to coordinate care**

A single named health or social care practitioner who is responsible for coordinating care. The named practitioner should:

- arrange an initial assessment of the person's needs, which should be face to face if possible
- provide information about available services and how to access them
- involve the person's family members or carers (as appropriate) in support and decision making
- give special consideration to the views of people who do not have capacity to make decisions about their care, in line with the principles of the Mental Capacity Act 2005
- ensure that people are aware of their rights to and the availability of local advocacy services, and if appropriate to the immediate situation an independent mental capacity advocate
- develop a care and support plan, and:
  - agree and review it with the involvement of the person, their family members or carers (as appropriate) and relevant professionals
  - specify in the plan when and how often it will be reviewed

- – evaluate and record progress towards the objectives at each review
- ensure it covers the management of any comorbidities
- provide a copy of the plan to the person and their family members or carers (as appropriate).

[NICE's guideline on [dementia](#), recommendations 1.3.1 and 1.3.2]

### *Equality and diversity considerations*

Barriers to communication can hinder people's understanding of how they can be involved in their care. These barriers could include: mental health problems, learning or cognitive difficulties; physical, sight, speech or hearing difficulties; or difficulties with reading, understanding or speaking English. Adjustments should be made to ensure that all people with dementia can work with their named coordinator of care to plan their care, with access to an advocate if needed.

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that, if needed, other ways of communicating (for example visual aids or simplified text) should be used.

## Quality statement 5: Activities to promote wellbeing

### *Quality statement*

People with dementia are supported to choose from a range of activities to promote wellbeing that are tailored to their preferences. [2013, updated 2019]

### *Rationale*

The symptoms of dementia make it harder for a person to take part in activities, to engage socially, to maintain their independence, to communicate effectively, to feel in control and to care for themselves. Providing enjoyable and health-enhancing activities that are suitable for the stage of dementia can help with this. Understanding the activities that a person prefers, and thinks are suitable and helpful, with the input of family and carers if needed, and adapting them to their strengths and needs, will make a person more likely to engage with the activities offered.

### *Quality measures*

#### **Structure**

a) Evidence of local arrangements to ensure that a range of activities are available that promote wellbeing for people with dementia.

**Data source:** Local data collection, for example, service specifications.

b) Evidence of local arrangements to ensure that people offering activities to promote wellbeing to people with dementia discuss the person's preferences with them and tailor the activities to these.

**Data source:** Local data collection, for example, service protocols.

c) Evidence of local arrangements to support access to a range of activities that promote wellbeing for people with dementia, such as transport options.

**Data source:** Local data collection, for example, service specifications.

#### **Process**

a) Proportion of people with dementia who discuss activities to promote wellbeing at a review of their care plan.

Numerator – the number in the denominator who discuss activities to promote wellbeing at a review of their care plan.

Denominator – the number of people with dementia.

**Data source:** Local data collection, for example, local audit of care plans.

b) Proportion of people with dementia who take part in activities to promote wellbeing that are tailored to their preferences.

Numerator – the number in the denominator who take part in activities to promote wellbeing that are tailored to their preferences.

Denominator – the number of people with dementia.

**Data source:** Local data collection, for example, local audit of patient records.

## Outcomes

a) Self-reported or carer-reported level of satisfaction with activities to promote wellbeing.

**Data source:** Local data collection, for example, patient surveys.

b) Self-reported or carer-reported quality of life of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia. The Dementia Quality of Life Measure (DEMQOL) is a patient-reported outcome measure to enable the assessment of health-related quality of life of people with dementia.

c) Level of independence of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia.

## What the quality statement means for different audiences

**Service providers** (such as local authorities, community care providers, dementia adviser services, community old age psychiatry services and memory clinics) ensure that systems are in place for people with dementia to discuss their preferences and needs, to choose activities to promote

wellbeing that are tailored to these, and to access the activities they have chosen.

**Health and social care practitioners** (such as occupational therapists, community psychiatric nurses, psychologists, care home nurses, healthcare assistants, activities coordinators, dementia advisers, wellbeing advisers and social workers) have a discussion with the person with dementia, and their families and carers if appropriate, about life experiences, circumstances, preferences, interests, strengths and needs. They are aware of the activities to promote wellbeing that are available locally and, based on this discussion, they help the person with dementia to choose activities that suit their preferences and needs.

**Commissioners** (such as local authorities and clinical commissioning groups) ensure that activities to promote wellbeing are available for people with dementia. They specify that providers offer people with dementia these activities based on a discussion of their preferences and needs.

**People with dementia** talk about their life experiences, circumstances, preferences, interests, strengths and needs with a professional and people involved in their care. They are told about suitable activities for improving their wellbeing, such as joining a local choir or walking group, and are supported to access the activities they choose.

### *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.4.1

### *Definitions of terms used in this quality statement*

#### **Activities to promote wellbeing**

Activities such as exercise, aromatherapy, art, gardening, baking, reminiscence therapy, music therapy, mindfulness and animal-assisted therapy.

[NICE's guideline on [dementia](#), full guideline and expert opinion]

#### **Tailored to their preferences**

Interventions that the person with dementia considers to be feasible, acceptable, enjoyable, suitable and helpful. The activities offered should be based on an understanding of that individual's unique set of life experiences, circumstances, preferences, strengths and needs.



[NICE's guideline on [dementia](#), full guideline]

### *Equality and diversity considerations*

Offers of activities need to take account of any mental health conditions and learning or physical disabilities. Any information provided should be accessible to people with additional needs, such as physical, sensory or learning disabilities. Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that if needed, other ways of communicating (for example, visual aids or simplified text) should be used.

## Quality statement 6: Managing distress

### *Quality statement*

People with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress. [2010, updated 2019]

### *Rationale*

People with dementia can become distressed, which can lead to symptoms such as increased aggression, anxiety, apathy, agitation, depression, delusions, hallucinations and sleep disturbances. But these behaviours may have other causes, including pain, delirium or inappropriate care. Understanding the causes of these behaviours and addressing them before offering treatment can prevent things getting worse and prevent any harm. It can also avoid the use of unnecessary interventions, such as antipsychotic medication and antidepressants, which may not manage the symptoms effectively.

### *Quality measures*

#### **Structure**

Evidence of local arrangements to ensure that people with dementia have a structured assessment before starting non-pharmacological or pharmacological treatment for distress.

**Data source:** Local data collection, for example, from local protocols.

#### **Process**

Proportion of people with dementia who have started non-pharmacological or pharmacological treatment for distress who had a structured assessment before starting treatment.

Numerator – the number in the denominator who had a structured assessment before starting treatment for distress.

Denominator – the number of people with dementia who have started non-pharmacological or pharmacological treatment for distress.

**Data source:** Local data collection, for example, local audit of patient records.

## Outcomes

a) Antipsychotic prescribing rates for people with dementia.

**Data source:** NHS Digital publishes data on prescribing of antipsychotic medication in its [recorded dementia diagnoses](#) data collection.

b) Self-reported or carer-reported quality of life of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia. The [Dementia Quality of Life Measure \(DEMQOL\)](#) is a patient-reported outcome measure to enable the assessment of health-related quality of life of people with dementia.

## *What the quality statement means for different audiences*

**Service providers** (such as community mental health services, secondary care services, general practices, local authorities and community care providers) ensure that professionals carry out a structured assessment to check for and address any clinical or environmental causes of distress before starting any treatment for distress for people with dementia.

**Health and social care professionals** (such as occupational therapists, community psychiatric nurses, psychiatrists, community matrons, clinical psychologists, neurologists, geriatricians, social workers and GPs) carry out a structured assessment for people with dementia showing signs of distress, such as agitation or aggression, to explore reasons for the distress before starting treatment. They involve family members or carers in the assessment if needed. As part of the assessment, they check for any clinical or environmental causes of distress, for example, pain, discomfort, delirium, inappropriate care, infection, boredom, noise or temperature, using assessment tools and involving other professionals as needed. They decide how to address any identified causes of distress, and whether another professional or specialist service needs to be involved.

**Commissioners** (such as local authorities, clinical commissioning groups and NHS England) ensure that services have systems in place to carry out a structured assessment for people with dementia to explore reasons for distress before starting treatment. The assessment should include checking for and addressing any clinical or environmental causes of distress, for example, pain, delirium or inappropriate care.

**People with dementia** have checks to see if there are any reasons why they are distressed and if so,

what can be done. Reasons might include pain, infection or not having the right care. Professionals address any of these issues before starting treatment for distress.

Family members and carers of people with dementia are involved in checks to see if something is causing the person's distress, if needed. Their involvement might be needed if, for example, the person with dementia lacks capacity, or needs support in communicating.

### *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.7.1

### *Definitions of terms used in this quality statement*

#### **Structured assessment**

A multifactorial assessment to explore reasons for distress by checking for clinical causes, environmental impacts, medication issues, communication issues and sensory issues, using appropriate assessment tools.

[Expert opinion and NICE's guideline on [dementia](#), recommendation 1.7.1]

#### **Non-pharmacological or pharmacological treatment for distress**

Non-pharmacological treatment might include psychosocial and environmental interventions, and personalised activities to promote engagement, pleasure and interest. These might include calming and distracting an agitated person, environmental management (for example, adjusting temperature, noise and lighting) and activities like arts and crafts, movement to music and accompanied walks. In addition, anxiety and depression may be treated using cognitive behavioural therapy, multisensory stimulation, relaxation and animal-assisted therapies. Pharmacological interventions might include antipsychotics, antidepressants and pain killers.

[Expert opinion and NICE's guideline on [dementia](#), recommendations 1.7.2, 1.7.3 and 1.7.9 and full guideline]

### *Equality and diversity considerations*

People with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating. Healthcare professionals caring for people with dementia should

establish the person's cognitive status, and whether they have any speech, language or other communication needs. They should also establish the person's current level of understanding; and whether they would like a person important to them to be present when discussing their distress.

Recommendation 1.1.2 in the NICE guideline on [dementia](#) highlights that, if needed, other ways of communicating (for example, visual aids or simplified text) should be used.

## Quality statement 7: Supporting carers

### *Quality statement*

Carers of people with dementia are offered education and skills training. [2010, updated 2019]

### *Rationale*

Family members and others caring for people with dementia often have high levels of stress due to the physical and mental challenges of caregiving, coping with other responsibilities, such as work or caring for children, health and mobility problems of their own, or financial issues. This affects their own physical and mental wellbeing. It is essential that informal carers have good support to enable them to manage the stresses and demands of caregiving and to fulfil their role. This includes both support for the specific challenges and practical tasks of caregiving, and support to address their own needs.

### *Quality measures*

#### **Structure**

a) Evidence that education and skills training are available for carers of people with dementia.

**Data source:** Local data collection, for example, from service specifications or local protocols.

b) Evidence that education and skills training are tailored to the needs and preferences of carers of people with dementia.

**Data source:** Local data collection, for example, from service specifications or local protocols.

c) Evidence that support is available for carers to be able to attend training knowing that the person they care for will be safe and cared for.

**Data source:** Local data collection, for example, from service specifications.

#### **Process**

a) Proportion of carers of people with dementia who have a discussion about education and skills training.

Numerator – the number in the denominator who have a discussion about education and skills training.

Denominator – the number of carers of people with dementia.

**Data source:** Local data collection, for example, local audit of care plans for carers.

b) Proportion of carers of people with dementia who take part in education and skills training.

Numerator – the number in the denominator who take part in education and skills training.

Denominator – the number of carers of people with dementia.

**Data source:** Local data collection, for example, local audit of care plans for carers.

## Outcomes

a) Carer-reported quality of life of carers of people with dementia.

**Data source:** Local data collection, for example, a survey of carers of people with dementia. The Public Health England [Dementia Profile](#) includes data on carer-reported quality-of-life score for people caring for someone with dementia.

b) Carer-reported level of satisfaction with the tailoring of the support to their needs and preferences.

**Data source:** Local data collection, for example, a survey of carers of people with dementia.

c) Self-reported or carer-reported quality of life of people with dementia.

**Data source:** Local data collection, for example, a survey of people with dementia. The [Dementia Quality of Life Measure](#) (DEMQOL) is a patient-reported outcome measure to enable the assessment of health-related quality of life of people with dementia.

## *What the quality statement means for different audiences*

**Service providers** (such as general practices, local authorities, community care providers, secondary care services and the voluntary sector) provide training and support for carers of people

with dementia and tailor this to the needs and preferences of the carer. They provide support so that carers can attend training knowing that the person they care for will be safe and well looked after.

**Health and social care professionals** (such as GPs, occupational therapists, community psychiatric nurses, psychiatrists, geriatricians, neurologists, clinical psychologists, practice nurses, hospital staff, Admiral nurses and social workers) have a discussion with carers of people with dementia about their needs and preferences for training and support. Based on this discussion, they help the carer to choose training and support that best suits them.

**Commissioners** (such as local authorities, clinical commissioning groups and NHS England) ensure that training and support is available for carers of people with dementia. They specify that this should be tailored to carer's needs and preferences. They ensure that support is provided so that carers can attend training knowing that the person they care for will be safe and well looked after.

**Carers of people with dementia** talk about the training and support they need and would like. They are told about training and support that would meet their needs and preferences. They receive support so that they can attend the training knowing that the person they care for will be safe and well looked after.

## *Source guidance*

Dementia: assessment, management and support for people living with dementia and their carers (2018) NICE guideline NG97, recommendation 1.11.1

## *Definitions of terms used in this quality statement*

### **Carers of people with dementia**

A person who provides unpaid support to a partner, family member, friend or neighbour who has dementia and could not manage without this help. This is distinct from a care worker, who is paid to support people. A legal definition of a carer can be found in the Care Act 2014.

[Adapted from the Think Local, Act Personal care and support jargon buster]

### **Education and skills training**

Training and support that includes:



- education about dementia, its symptoms and the changes to expect as the condition progresses
- developing personalised strategies and building carer skills
- training to help them provide care, including how to understand and respond to changes in behaviour
- training to help them adapt their communication styles to improve interactions with the person living with dementia
- advice on how to look after their own physical and mental health, and their emotional and spiritual wellbeing
- advice on planning enjoyable and meaningful activities to do with the person they care for
- information about relevant services (including support services and psychological therapies for carers) and how to access them
- advice on planning for the future.

The support should be:

- tailored to their needs and preferences and to what they want it to achieve (for example, providing information on carer's employment rights for carers who work or want to work)
- designed to help them support people living with dementia
- available at a location they can get to easily
- provided in a format suitable for them (for example, individual or group sessions, or online training and support)
- available from diagnosis and as needed after this.

[NICE's guideline on [dementia](#), recommendations 1.11.1 and 1.11.2]

### *Equality and diversity considerations*

Offers of training and support for carers of people with dementia need to take account of any physical or mental health conditions, learning or physical disabilities that make it difficult to access training and support.

## Update information

**June 2019:** This quality standard was updated and statements prioritised in 2010 and 2013 were replaced.

Statements are marked as:

- **[new 2019]** if the statement covers a new area for quality improvement
- **[2010 or 2013, updated 2019]** if the statement covers an area for quality improvement included in the 2010 or 2013 quality standard and has been updated.

Statements numbered 2, 4, 5, 6, and 7 in the 2010 version have been updated and are included in the updated quality standard, marked as **[2010, updated 2019]**. Statement 4 in the 2013 version has been updated and is included in the updated quality standard, marked as **[2013, updated 2019]**.

Statements 1, 3, 9 and 10 from the [2010 quality standard for dementia: support in health and social care](#) and statements 1, 2, 3, 5, 6, 7, 8, 9 and 10 from the [2013 quality standard for dementia: independence and wellbeing](#) are still supported by the evidence. These may be useful at a local level and are available as pdfs on the history tab.

## About this quality standard

NICE quality standards describe high-priority areas for quality improvement in a defined care or service area. Each standard consists of a prioritised set of specific, concise and measurable statements. NICE quality standards draw on existing NICE or NICE-accredited guidance that provides an underpinning, comprehensive set of recommendations, and are designed to support the measurement of improvement.

Expected levels of achievement for quality measures are not specified. Quality standards are intended to drive up the quality of care, and so achievement levels of 100% should be aspired to (or 0% if the quality statement states that something should not be done). However, this may not always be appropriate in practice. Taking account of safety, shared decision-making, choice and professional judgement, desired levels of achievement should be defined locally.

Information about [how NICE quality standards are developed](#) is available from the NICE website.

See [quality standard advisory committees](#) on the website for details of standing committee 3 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available on the [quality standard's webpage](#).

This quality standard has been included in the [NICE Pathway on dementia](#), which brings together everything we have said on a topic in an interactive flowchart.

NICE has produced a [quality standard service improvement template](#) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

NICE produces guidance, standards and information on commissioning and providing high-quality healthcare, social care, and public health services. We have agreements to provide certain NICE services to Wales, Scotland and Northern Ireland. Decisions on how NICE guidance and other products apply in those countries are made by ministers in the Welsh government, Scottish government, and Northern Ireland Executive. NICE guidance or other products may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

## *Improving outcomes*

This quality standard is expected to contribute to improvements in the following outcomes:

- dementia diagnosis rates
- time from referral to diagnosis of dementia
- hospital admission rates for people with dementia
- prescriptions for behavioural and psychological symptoms of dementia
- care home admissions for people with dementia
- length of hospital stay for people with dementia
- preferred place of death for people with dementia
- health-related quality of life for people with dementia
- health-related quality of life for carers of people with dementia.

It is also expected to support delivery of the Department of Health and Social Care outcome frameworks:

- [Adult social care outcomes framework](#)
- [NHS outcomes framework](#)
- [Public health outcomes framework for England](#).

### *Resource impact*

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the resource impact products for the source guidance to help estimate local costs:

- [resource impact report and template](#) for the NICE guideline on dementia: assessment, management and support for people living with dementia and their carers
- [costing statement](#) for the NICE guideline on dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset.

### *Diversity, equality and language*

During the development of this quality standard, equality issues were considered and [equality](#)

assessments are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

Commissioners and providers should aim to achieve the quality standard in their local context, in light of their duties to have due regard to the need to eliminate unlawful discrimination, advance equality of opportunity and foster good relations. Nothing in this quality standard should be interpreted in a way that would be inconsistent with compliance with those duties.

ISBN: 978-1-4731-3444-7

## *Endorsing organisations*

This quality standard has been endorsed by the following organisations, as required by the Health and Social Care Act (2012):

- [Department of Health and Social Care](#)
- [NHS England](#)

## *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 \(RCPsych\)](#)
- [Association of British Neurologists \(ABN\)](#)
- [Public Health England](#)
- [Royal College of Occupational Therapists \(RCOT\)](#)
- [Royal College of Physicians \(RCP\)](#)
- [Society and College of Radiographers \(SOR\)](#)
- [Royal College of General Practitioners \(RCGP\)](#)
- [Alzheimer's Society](#)
- [British Psychological Society \(BPS\)](#)