

# Care of dying adults in the last days of life

## NICE quality standard

### Draft for consultation

March 2017

## Introduction

This quality standard covers the clinical care of adults (18 years and over) who are dying during the last 2 to 3 days of life. It does not cover palliative care or 'end of life care' (often defined as care for people in the last year or so of a progressive disease) before the last few days of life. It does not include service delivery or care after death (such as care of the body, certification and bereavement).

This quality standard will complement the existing NICE quality standard for [end of life care for adults](#). A NICE guideline on [end of life care for adults in the last year of life: service delivery](#) is currently in development. The [end of life care for adults](#) quality standard will be updated following the publication of this guideline.

For more information see the [care of dying adults in the last days of life topic overview](#).

### ***Why this quality standard is needed***

Death and dying are inevitable and affect everyone. Around half a million people die each year in England. Good care in the last days of life meets the needs and reflects the preferences of people who are dying and those important to them. It enables people to make choices about their care and be as comfortable as possible until they die.

Although many people receive high-quality care at the end of their lives, independent reviews (such as the [review of the Liverpool Care Pathway](#) and [review of choice in end of life care](#) published by the Department of Health), audits (the Royal College of Physicians' [End of life care audit](#)) and surveys (the Office for

National Statistics' [National survey of bereaved people](#)) have identified variation in the care provided to people approaching the end of their lives.

Without an evidence-based approach to the care of dying people, there is a danger of placing tradition and familiar policies before meeting the needs of individuals and families. The Liverpool Care Pathway (LCP) for the Care of the Dying Adult, and its local derivatives, were widely adopted in the NHS and UK hospices until 2014. Although it was designed to bring values of 'good' end of life care from hospice settings to hospitals and elsewhere, it met with increasing criticism from the public, healthcare professions and the media. In 2013, the Government's independent review of the LCP led by Neuberger ([More Care, Less Pathway](#)) called for its withdrawal and replacement with an evidence-based and individualised care plan approach.

In 2015, NICE's guideline on [care of dying adults in the last days of life](#) was published in response to the need for an evidence-based guideline for the clinical care of the dying adult. This quality standard is based on this guideline and identifies priority areas for quality improvement. It aims to improve the quality of care provided to adults in the last days of life, and help reduce variations in care between providers and across settings.

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

- Recognising that a person is in the last days of life
- Symptom control
- Alignment of care with the preferences and needs of the dying person and those important to them
- Satisfaction with care and support provided.

### ***How this quality standard supports delivery of outcome frameworks***

NICE quality standards are a concise set of prioritised statements designed to drive measurable improvements in the 3 dimensions of quality – safety, experience and effectiveness of care – for a particular area of health or care. They are derived from

high-quality guidance, such as that from NICE or other sources accredited by NICE. This quality standard, in conjunction with the guidance on which it is based, should contribute to the improvements outlined in the following outcomes framework published by the Department of Health:

- [NHS outcomes framework 2016–17](#)

Table 1 shows the outcomes, overarching indicators and improvement areas from the outcomes framework that the quality standard could contribute to achieving. Indicators with technical specifications and data sources that exclude the target population of the quality standard, or where the target population is included but is considered unlikely to influence the measure, are not shown in the table.

**Table 1 [NHS Outcomes Framework 2016–17](#)**

Domain	Overarching indicators and improvement areas
4 Ensuring that people have a positive experience of care	<p><b>Overarching indicators</b></p> <p>4a Patient experience of primary care</p> <p>i GP services</p> <p>ii GP Out-of-hours services</p> <p>4b Patient experience of hospital care</p> <p><b>Improvement areas</b></p> <p><b>Improving the experience of care for people at the end of their lives</b></p> <p>4.6 Bereaved carers' views on the quality of care in the last 3 months of life</p>
Note: improvement area 4.6 is complementary to the overarching indicators in Domain 4.	

### ***Safety and people's experience of care***

Ensuring that care is safe and that people have a positive experience of care is vital in a high-quality service. It is important to consider these factors when planning and delivering services relevant to care of dying adults in the last days of life.

NICE has developed guidance and associated quality standards on patient experience in adult NHS services and service user experience in adult mental health services (see [patient experience in adult NHS services](#) and [service user experience in adult mental health services](#)) which should be considered alongside this quality standard. They specify that people receiving care should be treated with dignity,

have opportunities to discuss their preferences, and be supported to understand their options and make fully informed decisions. They also cover the provision of information to people using services. Quality statements on these aspects of patient experience are not usually included in topic-specific quality standards. However, recommendations in the development sources for quality standards that affect people's experience of using services and are specific to the topic are considered during quality statement development.

### ***Coordinated services***

Services should be commissioned from and coordinated across all relevant agencies encompassing care of dying adults in the last days of life. A person-centred, integrated approach to providing services is fundamental to delivering high-quality care to adults in the last hours or days of life across all settings.

The Health and Social Care Act 2012 sets out a clear expectation that the care system should consider NICE quality standards in planning and delivering services, as part of a general duty to secure continuous improvement in quality.

Commissioners and providers of health and social care should refer to the library of NICE quality standards when designing high-quality services. Other quality standards that should also be considered when choosing, commissioning or providing high-quality care of dying adults in the last days of life are listed in [related quality standards](#).

### **Resource impact considerations**

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 report](#) for the NICE guideline on care of dying adults in the last days of life to help estimate local costs.

### **Training and competencies**

The quality standard should be read in the context of national and local guidelines on training and competencies. All health and social care practitioners involved in assessing, caring for and treating adults in the last days of life should have sufficient and appropriate training and competencies to deliver the actions and interventions

described in the quality standard. Quality statements on staff training and competency are not usually included in quality standards. However, recommendations in the development source on specific types of training for the topic that exceed standard professional training are considered during quality statement development.

### **Role of families and carers**

Quality standards recognise the important role families and carers have in supporting adults in the last days of life. If appropriate, health and social care practitioners should ensure that family members and carers are involved in the decision-making process about investigations, treatment and care.

### **List of quality statements**

[Statement 1](#). Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering.

[Statement 2](#). Adults in the last days of life are given care that is in accordance with their stated preferences and responsive to their changing preferences.

[Statement 3](#). Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use and dosage.

[Statement 4](#). Adults in the last days of life have their hydration status assessed daily, and a discussion about the risks and benefits of clinically assisted hydration.

### **Questions for consultation**

#### ***Questions about the quality standard***

**Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?

**Question 2** Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?

**Question 3** Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please submit your example to the [NICE local practice collection](#) on the NICE website. Examples of using NICE quality standards can also be submitted.

**Question 4** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

### ***Questions about the individual quality statements***

**Question 5** For draft quality statement 2: Draft statement 2 covers the capture of a person's preferences in the last days of life, and the provision of care that accords with their preferences. Does this statement adequately address individualised care planning in the last days and hours of life?

**Question 6** For draft quality statement 3: Does this statement adequately represent an individualised approach to prescribing anticipatory medicines for adults in the last days of life?

**Question 7** For draft quality statement 4: Does this statement address the most important area for quality improvement in relation to hydration for people in the last days of life?

## Quality statement 1: Recognising when a person may be nearing death

### ***Quality statement***

Adults who have signs and symptoms that suggest they may be in the last days of life are monitored for further changes to help determine if they are nearing death, stabilising or recovering.

### ***Rationale***

Identifying that a person is in the last days of life is vital to ensure that appropriate care is provided. To recognise that death is imminent, a range of signs and symptoms are observed, if the dying person's clinical course allows for such observations. However, recognising and weighing up factors that may indicate someone is in the last days of life can be a complex and difficult task. There can be ambiguous and conflicting signs and symptoms, and some changes in condition may be potentially reversible. For example, a person thought to be close to death may start to show signs of recovery. Some signs and symptoms of improvement may be temporary, or may represent a true recovery. Therefore, it is important to continue to assess the person's signs and symptoms. Uncertainty in recognising dying can be reduced by seeking advice from those experienced in providing end of life care, such as specialist palliative care teams.

### ***Quality measures***

#### **Structure**

a) Evidence of local arrangements and systems to ensure that it is recognised when an adult may be entering the last days of their life.

**Data source:** Local data collection.

b) Evidence of local arrangements and systems to monitor signs and symptoms of adults thought to be in the last days of life; and to review changes in condition of adults to help determine if they are nearing death, stabilising or recovering.

**Data source:** Local data collection.

## Process

a) Proportion of adult deaths with documented evidence that their signs and symptoms were monitored in the last days of life.

Numerator – the number in the denominator in which the care records show evidence of monitoring of signs and symptoms in the 3 days prior to the actual death.

Denominator – the number of adult deaths.

**Data source:** Local data collection.

b) Proportion of adult deaths with documented evidence that it was recognised that the person was likely to die in the coming hours or days.

Numerator – the number in the denominator in which the care records show recognition that the adult is in the last days of life.

Denominator – the number of adult deaths.

**Data source:** Local data collection. National and trust level data on people who died in hospital for whom it was recognised that they would probably die in the coming hours or days are reported in [End of Life Care Audit – Dying in Hospital report for England](#).

c) Proportion of adults who have the recognition that they are thought to be dying reviewed.

Numerator – the number in the denominator where recognition that the adult may die is reviewed.

Denominator – the number of adults with documented recognition that they may die within the coming hours or days.

**Data source:** Local data collection. National data on people who died in hospital and had the recognition that they were dying reviewed are reported in [End of Life Care Audit – Dying in Hospital report for England](#).



**Outcome**

a) Proportion of adults in the last days of life that are told that they may be close to death (unless they do not wish to be informed).

**Data source:** Local data collection.

b) Proportion of adults cared for in accordance with their preferences in the last days of life.

**Data source:** Local data collection.

***What the quality statement means for service providers, healthcare practitioners, and commissioners***

**Service providers** (such as hospitals, hospices, GP practices and district nursing services) ensure that systems and procedures are in place to identify adults who may be in the last days of life; to monitor changes in the signs and symptoms of such adults; and to ensure that staff experienced in end of life care are available to offer advice to less experienced colleagues.

**Healthcare practitioners** (such as secondary care doctors, nurses, GPs and district nurses) ensure that they assess adults for signs and symptoms that may suggest a person is in the last hours or days of life; continue to monitor for changes in signs and symptoms including the possibility of stabilising or recovering; review the recognition that a person may be dying; and seek experience from colleagues with more experience or providing end of life care where there is uncertainty.

**Commissioners** (such as clinical commissioning groups) use contractual and service specification arrangements to ensure that providers identify adults who may be in the last days of life and monitor them for further changes.

***What the quality statement means for patients, people using services and carers***

**Adults who are thought to be dying** are checked at least once a day for symptoms and changes that might show that they are nearing death, and also for signs that their condition is stable or might be improving.

## **Source guidance**

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31 recommendations 1.1.2, 1.1.3 and 1.1.6

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

### **Signs and symptoms**

Signs and symptoms that suggest a person may be in the last days of life include:

- signs such as agitation, Cheyne–Stokes breathing, deterioration in level of consciousness, mottled skin, noisy respiratory secretions and progressive weight loss
- symptoms such as increasing fatigue and loss of appetite
- functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

[[Care of dying adults in the last days of life](#) (NICE guideline NG31), recommendation 1.1.2]

### **Monitored for further changes**

Assessment of changes in the person, including their signs and symptoms, with specialist advice sought when there is a high level of uncertainty because of conflicting results. Assessment occurs at least every 24 hours. More frequent assessment may be required as symptoms can change quickly.

[Adapted from [Care of dying adults in the last days of life](#) (NICE guideline NG31), recommendation 1.1.6]

## Quality statement 2: Shared decision-making

### ***Quality statement***

Adults in the last days of life are given care that is in accordance with their stated preferences and responsive to their changing preferences.

### ***Rationale***

People who are dying may want to be involved in decisions about the care they receive and how it is delivered. Some will have already expressed preferences for care, for example, through advance care planning, and may have set personal goals for the time they have left. These may include preferences on care setting, symptom management and anticipated care needs. Capturing, documenting and sharing this information can ensure that the planning and delivery of care reflects personal preferences. A person's wishes or needs may change in the last days of life, and so their preferences should be reviewed and updated throughout this period.

### ***Quality measures***

#### **Structure**

a) Evidence of local arrangements to identify existing advance care plans or advance decisions for adults recognised to be in the last days of life.

**Data source:** Local data collection.

b) Evidence of local arrangements to ensure that adults in the last days of life, and those important to them, are asked about preferences for their care.

**Data source:** Local data collection.

c) Evidence of local arrangements to ensure that adults in the last days of life are cared for in accordance with their stated preferences.

**Data source:** Local data collection.

## **Process**

a) Proportion of adults in the last days of life who have documented preferences for their care in the last days of life.

Numerator – the number in the denominator with care records that include preferences for care in the last days of life.

Denominator – the number of adults recognised as being in the last days of life.

**Data source:** Local data collection.

b) Proportion of adults who have their preferences for care reviewed in the last days of life.

Numerator – the number in the denominator with care records that show their preferences for care in the last days of life were reviewed during the last days of life.

Denominator – number of adults recognised as being in the last days of life with documented preferences for their care in this period.

**Data source:** Local data collection.

c) Proportion of adults cared for in accordance with their preferences in the last days of life.

Numerator – the number in the denominator whose care was provided in accordance with the documented preferences for their care.

Denominator – number of adults recognised as being in the last days of life with documented preferences for their care in this period.

**Data source:** Local data collection.

## **Outcome**

Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life.

**Data source:** Local data collection.

### ***What the quality statement means for service providers, healthcare practitioners and commissioners***

**Service providers** (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place to identify previously stated and current preferences for care of adults in the last hours or days of life; to review these preferences; and to deliver care that respects these preferences.

**Healthcare practitioners** (such as doctors, nurses, GPs and district nurses) discuss preferences for care with adults entering the last days of life, and those important to them; ask if they have any advance care plans or other existing preferences for their care; ask if they have any new or changed preferences throughout their care; record preferences in an individualised care plan; and deliver care that respects these preferences.

**Commissioners** (such as clinical commissioning groups) use contractual and service specification arrangements to ensure that they commission services from providers that identify previously stated and current preferences for care of adults in the last days of life; review these preferences; and deliver care that respects these preferences.

### ***What the quality statement means for patients, people using services and carers***

**Adults who are in the last days of their life** have discussions with a member of their care team about the care and support they would like, whether they have any existing preferences, and who else should be involved in making decisions about their care. Discussions continue throughout the last days of life as people may change their minds about the type of care they want, or their needs may change. Discussions, preferences and decisions on care are recorded in an individual care plan.

### ***Source guidance***

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31 recommendations 1.2.5, 1.3.1, 1.3.2, 1.3.5 and 1.3.7

***Equality and diversity considerations***

Adults in the last days of life with dementia, cognitive impairment, learning disabilities or language barriers may have difficulties communicating their preferences for care. Healthcare practitioners caring for adults in the last days of life should establish the person's cognitive status, and if they have any speech, language or other communication needs; their current level of understanding; and if 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; and people receiving information should have access to an interpreter or advocate if needed.

***Question for consultation***

Draft statement 2 covers the capture of a person's preferences in the last days of life, and the provision of care that accords with their preferences. Does this statement adequately address individualised care planning in the last days and hours of life?

## Quality statement 3: Anticipatory prescribing

### ***Quality statement***

Adults in the last days of life who are likely to need symptom control are prescribed anticipatory medicines with individualised indications for use and dosage.

### ***Rationale***

As a person approaches the last few days of life, changes in their condition may lead to changes in symptoms, the emergence of new symptoms or changes in their ability to take medicines to manage their symptoms (such as swallowing oral medicines). Symptoms that are common in the last days of life include pain, breathlessness, anxiety, nausea and vomiting, and noisy respiratory secretions. Poor control of symptoms can lead to distress for the person who is dying and those close to them. Symptoms are usually managed using regular medications, and extra needs arising from current symptoms using prn or 'as required' prescriptions. Anticipating new symptoms that may arise and prescribing medicines in advance to manage them allows administration as soon as problematic symptoms arise. Basing anticipatory prescribing on assessments of the likely symptoms of individual patients, and including indications for use, dosage and route of administration of any prescribed medicines, helps ensure timely and appropriate use of drugs.

### ***Quality measures***

#### **Structure**

Evidence of local arrangements to ensure that adults in the last days of life are assessed for likely symptoms and are prescribed anticipatory medicines.

***Data source:*** Local data collection.

#### **Process**

Proportion of adults in the last days of life prescribed anticipatory medicines using an individualised approach.

Numerator – the number in the denominator with care records that indicate anticipatory medicines have been prescribed based on an assessment of likely individual symptoms, with indications for use and dosage specified for the person.

Denominator – number of adults in the last days of life.

**Data source:** Local data collection.

### **Outcome**

a) Proportion of adults in the last days of life that have problematic symptoms controlled as they arise.

**Data source:** Local data collection.

b) Proportion of bereaved people who feel satisfied with the care provided in the last days of the person's life.

**Data source:** Local data collection.

### ***What the quality statement means for service providers, healthcare practitioners and commissioners***

**Service providers** (such as hospitals, hospices and GP practices) ensure that systems are in place to assess adults in the last days of life for likely symptoms; to prescribe anticipatory medicines for the symptoms using an individualised approach; and to ensure access to medicines.

**Healthcare practitioners** (such as secondary care doctors, specialist palliative care doctors, GPs, non-medical prescribers) ensure that they assess what symptoms are likely to occur for an individual in the last days of life; discuss what medicines might be needed with the dying person, those important to them, and other members of the team caring for them; and prescribe anticipatory medicines appropriate to the individual anticipated needs of the dying person, including indications for use, dosage and route of administration.

**Commissioners** (such as clinical commissioning groups) use contractual and service specification arrangements to ensure that providers they commission



services from prescribe anticipatory medicines using an individualised approach to adults in the last days of life and ensure access to medicines.

### ***What the quality statement means for patients, people using services and carers***

**Adults who are in the last days of life** are prescribed medicines in advance for symptoms that might happen in the future. This avoids delay in getting medicines that might be needed quickly. Anticipatory medicines are prescribed based on the symptoms that are likely to develop for each person.

### ***Source guidance***

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31 recommendations 1.6.1, 1.6.2, 1.6.3 and 1.6.4

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

#### **Anticipatory medicines**

Medication prescribed in anticipation of symptoms, designed to enable rapid relief at whatever time the patient develops distressing symptoms.

[\[Care of dying adults in the last days of life](#) (NICE guideline NG31), full guideline]

### ***Question for consultation***

Does this statement adequately represent an individualised approach to prescribing anticipatory medicines for adults in the last days of life?

## Quality statement 4: Maintaining hydration

### ***Quality statement***

Adults in the last days of life have their hydration status assessed daily, and a discussion about the risks and benefits of clinically assisted hydration.

### ***Rationale***

Maintaining hydration at the end of life can be controversial and emotive. Drinking is a basic human need, but as death approaches the desire to take in fluid can diminish. Some people who want to drink may not be able to do so, and may need support to drink or may need clinically assisted hydration. Inadequate hydration can result in distressing symptoms such as thirst and delirium, and can sometimes lead to death. However, drinking and clinically assisted hydration are not without risks; there can be swallowing problems, risk of aspiration, and overhydration can cause swelling and breathing difficulties. Clinically assisted hydration may relieve distressing symptoms related to dehydration, but it is uncertain if giving it will prolong life or extend the dying process; or if not giving it will hasten death. At the end of life, a person's hydration needs may change with their condition. Daily assessment enables changes in hydration status to be identified, along with problems with oral hydration and any need for clinically assisted hydration. Assessment also allows the benefits and risks of clinically assisted hydration to be identified for an individual person. Discussing the risks and benefits of clinically assisted hydration with the dying person, and those important to them, can improve their understanding of hydration issues and allow their wishes and preferences to be expressed and taken into account when decisions are made on clinically assisted hydration.

### ***Quality measures***

#### **Structure**

a) Evidence of local arrangements to ensure that adults in the last days of their lives have their hydration status assessed daily.

***Data source:*** Local data collection.

b) Evidence of local arrangements to ensure that adults in the last days of their lives, and those important to them, have discussions on the potential risks and benefits of clinically assisted hydration.

**Data source:** Local data collection.

### **Process**

a) Proportion of adults in the last days of life who have their hydration status assessed daily.

Numerator – the number in the denominator who have their hydration status assessed at least once daily.

Denominator – the number of adults in the last days of life.

**Data source:** Local data collection.

b) Proportion of adults in the last days of life who have a discussion about the risks and benefits of clinically assisted hydration.

Numerator – the number in the denominator whose individual care plan shows that there has been a discussion about the risks and benefits of clinically assisted hydration.

Denominator – the number of adults in the last days of life.

**Data source:** Local data collection.

### **Outcome**

a) Proportion of adults in the last days of life with symptoms of dehydration and overhydration.

**Data source:** Local data collection.

b) Proportion of adults in the last days of life, and those important to them, who understand hydration issues and the aims of care.

**Data source:** Local data collection.

c) Proportion of bereaved people who feel satisfied that the person who has died was supported to drink or receive fluids if they wished.

**Data source:** Local data collection. National data on bereaved people who agreed that the person who died had support to drink or receive fluid if they wished in the last 2 days of life are reported in the [National Survey of Bereaved People \(VOICES\)](#).

### ***What the quality statement means for service providers, healthcare practitioners, and commissioners***

**Service providers** (such as hospitals, hospices, GP practices and district nursing services) ensure that systems are in place to ensure that adults in the last days of life have their hydration status assessed daily. They ensure that staff are aware of the potential risks and benefits of clinically assisted hydration and discuss these with the dying person and those important to them, and capture their wishes and preferences. They also ensure that the need for clinically assisted hydration is reviewed in accordance with those wishes and preferences.

**Healthcare practitioners** (such as secondary care doctors, nurses, GPs, hospice doctors and district nurses) ensure that they assess the hydration status of adults in the last days of life daily, including observations for signs and symptoms of overhydration and dehydration. They use this information to identify the potential risks and benefits of clinically assisted hydration for the person, and discuss these with the person who is dying, and those important to them, and identify their wishes and preferences. They also review the need for clinically assisted hydration taking into account the person's wishes and preferences.

**Commissioners** (such as clinical commissioning groups) use contractual and service specification arrangements to ensure that providers they commission services from assess the hydration needs of adults in the last days of life daily; discuss the potential risks and benefits of clinically assisted hydration with the dying person and those important to them; and review the need for clinically assisted hydration in accordance with their wishes and preferences.

## ***What the quality statement means for patients, people using services and carers***

**Adults who are in the last days of life** are checked every day to make sure they are drinking enough to stay hydrated. If the person needs help to stay hydrated, their doctor might suggest giving them fluids through a drip or tube to see if this helps. This might not be the best option for everyone, and the risks and benefits will be explained by the doctor.

### ***Source guidance***

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31 recommendations 1.4.4 and 1.4.5

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

### ***Clinically assisted hydration***

Providing fluids in the form of a drip, usually either intravenously or subcutaneously (a technique known as hypodermoclysis) or via a nasogastric tube or gastrostomy to prevent dehydration. It does not include assisting a person to drink.

[Adapted from [Care of dying adults in the last days of life](#) (NICE guideline NG31), glossary in the full version of the guideline]

### ***Equality and diversity considerations***

Adults in the last days of life with dementia, cognitive impairments, learning disabilities or language barriers may have difficulties communicating. Healthcare practitioners caring for adults in the last days of life should establish the person's cognitive status, and if they have any speech, language or other communication needs; their current level of understanding; and if they would like a person important to them to be present when discussing hydration. All information provided should be accessible, as far as possible, to people with cognitive problems; and people receiving information should have access to an interpreter or advocate if needed.

***Question for consultation***

Does this statement address the most important area for quality improvement in relation to hydration for people in the last days of life?

## Status of this quality standard

This is the draft quality standard released for consultation from 29 September to 27 October 2016. It is not NICE's final quality standard on care of dying adults in the last days of life. The statements and measures presented in this document are provisional and may change after consultation with stakeholders.

Comments on the content of the draft standard must be submitted by 5pm on 27 October 2016. All eligible comments received during consultation will be reviewed by the quality standards advisory committee and the quality statements and measures will be refined in line with the quality standards advisory committee's considerations. The final quality standard will be available on the [NICE website](#) from March 2017.

## Using the quality standard

### *Quality measures*

The quality measures accompanying the quality statements aim to improve the structure, process and outcomes of care in areas identified as needing quality improvement. They are not a new set of targets or mandatory indicators for performance management.

We have indicated if current national indicators exist that could be used to measure the quality statements. If there is no national indicator that could be used to measure a quality statement, the quality measure should form the basis for audit criteria developed and used locally.

See [how to use quality standards](#) for more information, including advice on using quality measures.

### *Levels of achievement*

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, NICE recognises that this may not always be

appropriate in practice, taking account of safety, choice and professional judgement, and therefore desired levels of achievement should be defined locally.

NICE's [quality standard service improvement template](#) helps providers to make an initial assessment of their service compared with a selection of quality statements. It includes assessing current practice, recording an action plan and monitoring quality improvement. This tool is updated monthly to include new quality standards.

### ***Using other national guidance and policy documents***

Other national guidance and current policy documents have been referenced during the development of this quality standard. It is important that the quality standard is considered alongside the documents listed in [development sources](#).

## **Diversity, equality and language**

During the development of this quality standard, equality issues have been considered and [equality assessments](#) are available.

Good communication between health, public health and social care practitioners and adults in the last days of life is essential. Treatment, care and support, 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. Adults should have access to an interpreter or advocate if needed.

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.

## **Development sources**

Further explanation of the methodology used can be found in the [quality standards process guide](#).



## ***Evidence sources***

The documents below contain recommendations from NICE guidance or other NICE-accredited recommendations that were used by the quality standards advisory committee to develop the quality standard statements and measures.

- [Care of dying adults in the last days of life](#) (2015) NICE guideline NG31

## ***Policy context***

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

- Department of Health (2015) [Government response to the House of Commons Health Select Committee report on end of life care](#)
- House of Commons Health Select Committee (2015) [End of life care](#)
- National Palliative and End of Life Care Partnership (2015) [Ambitions for palliative and end of life care: A national framework for local action 2015-2020](#)
- NHS England (2015) [Transforming end of life care in acute hospitals: The route to success 'how to' guide](#)
- Leadership Alliance for the Care of Dying People (2014) [One chance to get it right](#)
- Department of Health (2013) [More care, less pathway: a review of the Liverpool Care Pathway](#)

## ***Definitions and data sources for the quality measures***

- NICE (2015) [Care of dying adults in the last days of life \(NICE guideline NG31\)](#)

## **Related NICE quality standards**

### ***Published***

- [Patient experience in adult NHS services](#) (2012) NICE quality standard 15
- [End of life care for adults](#) (2011) NICE quality standard 13

### ***In development***

- [Older people with social care needs and multiple long-term conditions.](#)  
Publication expected September 2016.

### ***Future quality standards***

This quality standard has been developed in the context of all quality standards referred to NICE, including the following topics scheduled for future development:

- End of life care for infants, children and young people
- Pain management (young people and adults)
- Service user and carer experience of social care
- Supporting decision-making in people who lack mental capacity

The full list of quality standard topics referred to NICE is available from the [quality standards topic library](#) on the NICE website.

## **Quality standards advisory committee and NICE project team**

### ***Quality standards advisory committee***

This quality standard has been developed by quality standards advisory committee 4. Membership of this committee is as follows:

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Lay member

#### **Mrs Moyra Amess**

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**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.

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

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.

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