NICE National Institute for
Health and Care Excellence

Care of dying adults in the last days of life

Quality standard
Published: 2 March 2017

www.nice.org.uk/guidance/qs144

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This standard is based on NG31.

This standard should be read in conjunction with QS13, QS15 and QS184.

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Quality statement 1: Assessing signs and symptoms

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

By continuing to assess signs and symptoms that suggest someone is in the last days of their life, responsive and compassionate care can be provided to ensure that the person is as comfortable as possible if their condition continues to deteriorate. Recognising and assessing indications that someone is in the last days of life can be complex, and sometimes people have ambiguous and conflicting signs and symptoms. People can show signs of recovery, which may continue or which may be temporary. Uncertainty can be reduced by seeking advice from those experienced in providing end of life care, such as specialist palliative care teams.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local protocols on recognising adults may be entering the last days of life.

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 a person's condition to help determine if they are nearing death, stabilising or recovering.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from patient records.

Process

a) Proportion of adult deaths with documented evidence that it was recognised that the person was in the last days of life.

Numerator – the number in the denominator in which the care records show it was recognised that the adult was in the last days of life.

Denominator – the number of adult deaths.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from GP and community nurse patient records for people cared for outside of hospital. The National Audit of Care at the End of Life: dying in hospital collects hospital level information on when recognition that a patient might die is first documented and the date of death.

b) Proportion of adults recognised as being in the last days of life with documented evidence that their signs and symptoms were monitored at least daily.

Numerator – the number in the denominator in which the care records show evidence of monitoring of signs and symptoms at least daily.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from audits of patient records. The National Audit of Care at the End of Life: dying in hospital collects information on whether there is documented evidence that a hospital patient's symptoms were reviewed daily.

Outcome

Proportion of adults thought to be in the last days of life given care appropriate to whether they were nearing death, stabilising or recovering.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example, from audits of patient care records and individualised care plans.

What the quality statement means for different audiences

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 and to monitor for changes in their signs and symptoms. They also ensure that staff experienced in end of life care are available to offer advice to less experienced colleagues.

Healthcare professionals (such as secondary care doctors, nurses, GPs, hospice doctors and district nurses) assess adults for signs and symptoms that may suggest a person is in the last days of life, and use the assessments and other information gathered from the person, those important to them and those providing care to them to help determine whether the person is nearing death, deteriorating, stable or improving. They continue to monitor for changes in signs and symptoms, including the possibility of stabilising or recovering, and review the recognition that a person may be dying. If there is uncertainty, they seek advice from colleagues with more experience of providing end of life care.

Commissioners 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.

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, so that they can be given the right care.

Source guidance

Care of dying adults in the last days of life. NICE guideline NG31 (2015), 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, reduced desire for food and fluid, and deterioration in swallowing function
- functional observations such as changes in communication, deteriorating mobility or performance status, or social withdrawal.

[Adapted from NICE's guideline on care of dying adults in the last days of life, 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, but more frequent assessment may be needed because symptoms can change quickly. The use of the word 'monitored' does not necessarily imply use of equipment or invasive tests; changes in signs and symptoms can be gathered from talking with, observing and examining the person. [Adapted from NICE's guideline on care of dying adults in the last days of life, recommendation 1.1.6]

Quality statement 2: Individualised care

Quality statement

Adults in the last days of life, and the people important to them, are given opportunities to discuss, develop and review an individualised care plan.

Rationale

Care at the end of life should be responsive to the personal needs and preferences of the person who is dying. Discussions with the person can identify any existing expressed preferences for care, such as advance care plans, and explore their goals and wishes, preferred care setting, current and anticipated care needs and any cultural, religious or social preferences. This information will be captured in an individualised care plan. Opportunities for discussion should continue to be given so the plan can reflect any changes in the person's wishes or needs in the last days of their life.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that adults in the last days of life have their individualised care plans reviewed.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example, from patient records and care plans.

Process

a) Proportion of adults recognised as being in the last days of life, and the people important to them, who are given opportunities to discuss and develop an individualised care plan.

Numerator – the number in the denominator with care records that show the person who was in the last days of life, and the people important to them, were given opportunities to discuss and develop an individualised care plan.

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

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example, from audits of patient care records. The National Audit of Care at the End of Life: dying in hospital measures the number of patients whose case notes have documented evidence that they participated in personalised care and support planning (advance care planning) conversations.

b) Proportion of adults recognised as being in the last days of life who have an individualised care plan.

Numerator – the number in the denominator with an individualised care plan.

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

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example from audits of patient care records. The National Audit of Care at the End of Life: dying in hospital collects information on whether patients who died in hospital had an individualised plan of care addressing their end of life care needs.

c) Proportion of adults recognised as being in the last days of life whose individualised care plan was followed.

Numerator – the number in the denominator whose individualised care plan was followed.

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

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example from audits of patient care records. The National Audit of Care at the End of Life: dying in hospital collects information on whether care for patients who died in hospital was uncoordinated or not, and information on actions to meet the needs of the dying person.

Outcome

Proportion of adults who feel they have choice and control over their care in the last days of life.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example using feedback from adults in the last days of life and people important to them.

What the quality statement means for different audiences

Service providers (such as hospitals, hospices, GP practices, district nursing services, nursing homes and social care providers) ensure that individualised care plans are created for adults in the last days of life, and that staff providing care to people who are dying give them opportunities to discuss their preferences and needs and document these in the care plan.

Healthcare professionals (such as doctors, nurses, GPs, hospice doctors and district nurses) give adults in the last days of life, and the people important to them, opportunities to discuss, develop and review an individualised care plan. They ask and explore if they have any advance care plans or other existing preferences for their care, and check if they have any new or changed preferences throughout their care. They document the discussions in an individualised care plan.

Commissioners use contractual and service specification arrangements to ensure that providers use individualised care plans to deliver and coordinate care for adults in the last days of life, and also give opportunities for the person who is dying and the people important to them to discuss, develop and review their care plans.

Adults who are in the last days of life are given chances to discuss the care and support they would like with a member of their care team. This includes their current needs, preferences, any decisions they have already made, and who else should be involved in discussing and making decisions about their care. Offers of 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. NICE guideline NG31 (2015), recommendations 1.2.5, 1.3.1, 1.3.2, 1.3.5 and 1.3.7

Definitions of terms used in this quality statement

Individualised care plan

A plan prepared in discussion with the dying person, the people important to them and the multiprofessional team caring for them which includes the dying person's:

- personal goals and wishes
- preferred care setting
- current and anticipated care needs including:
  - preferences for symptom management and maintaining hydration
  - needs for care after death, if any are specified
- resource needs.

[Adapted from NICE's guideline on care of dying adults in the last days of life, recommendation 1.3.5]

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 professionals 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.

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, dosage and route of administration.

Rationale

As a person approaches the last few days of their life, changes in their condition may lead to changes in existing symptoms, the emergence of new symptoms or changes in the person's ability to take medicines to manage their symptoms (such as swallowing oral medicines). Prescribing medicines in anticipation can avoid a lapse in symptom control, which could otherwise cause distress for the person who is dying and those close to them. The drugs prescribed must be appropriate to the individualised anticipated needs of the dying person and include written clinical indications (current or anticipated), dosage and routes of administration (some drugs may be prescribed for more than one indication at different doses).

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Process

a) Proportion of adults recognised as being in the last days of life who have their prescribing needs assessed for symptoms likely to occur in their last days of life.

Numerator – the number in the denominator whose prescribing needs have been assessed for symptoms likely to occur in the last days of life.

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

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example using audits of patient care records.

b) Proportion of adults recognised as being in the last days of life prescribed anticipatory medicines with individualised indications for use, dosage and route of administration.

Numerator – the number in the denominator with care records that show anticipatory medicines have been prescribed with individualised indications for use, dosage and route of administration.

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

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example using audits of patient care records. The National Audit of Care at the End of Life: dying in hospital collects information for patients who died in hospital on whether anticipatory medication was prescribed for symptoms likely to occur in the last days of life and on whether the medication was individualised.

Outcome

Proportion of adults who had their key symptoms controlled in the last days of life.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example using audits of patient care records.

What the quality statement means for different audiences

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 likely symptoms using an individualised approach, and to ensure access to medicines.

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

Commissioners use contractual and service specification arrangements to ensure that providers prescribe anticipatory medicines using an individualised approach for adults in the last days of life and ensure access to medicines.

Adults who are in the last days of life are prescribed medicines in advance for symptoms that might happen in the future. This avoids a delay in getting medicines that might be needed quickly when symptoms develop. These medicines are prescribed based on the individual needs of the person.

Source guidance

Care of dying adults in the last days of life. NICE guideline NG31 (2015), recommendation 1.6.1

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. Drugs prescribed in anticipation may include previous or current prescriptions, sometimes with a change in the route of administration, and newly prescribed drugs for anticipated new symptoms. [NICE's full guideline on care of dying adults in the last days of life and expert opinion]

Quality statement 4: Hydration

Quality statement

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

Rationale

Drinking is a basic human need, but as death approaches the desire to take in fluid can diminish. Daily assessment enables changes in hydration status and associated symptoms to be identified, along with problems with oral hydration and any need for clinically assisted hydration. Discussing the risks and benefits of options for hydration with the person who is dying, and those important to them, allows their wishes and preferences to be taken into account. The normal route of hydration is oral, but some people who want to drink may not be able to do so, and may need support to drink or may benefit from 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 and the risk of aspiration with drinking, and excessive assisted hydration can cause swelling and breathing difficulties.

Quality measures

The following measures can be used to assess the quality of care or service provision specified in the statement. They are examples of how the statement can be measured, and can be adapted and used flexibly.

Structure

Evidence of local arrangements to ensure that adults in the last days of life, and the people important to them, have discussions about the risks and benefits of hydration options.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example from service specifications or local protocols.

Process

a) Proportion of adults recognised as being 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 daily.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from audits of patient care records. The National Audit of Care at the End of Life: dying in hospital collects information on evidence of review of hydration options in the last days of life for patients who died in hospital.

b) Proportion of adults recognised as being in the last days of life who have a discussion about the risks and benefits of hydration options.

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

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from audits of patient care records and individual care plans. The National Audit of Care at the End of Life: dying in hospital collects information on evidence of communication about hydration with the patient for patients who died in hospital.

Outcome

a) Proportion of adults who felt comfortable in the last days of life.

Data source: Data can be collected locally by healthcare professionals and provider organisations, for example using feedback from adults in the last days of life and the people important to them.

b) 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: Data can be collected locally by healthcare professionals and provider organisations, for example using feedback from bereaved people. The National Audit of Care at the End of Life: dying in hospital collects information on bereaved people who agreed that the person who died in hospital had support to drink or receive fluid if they wished.

What the quality statement means for different audiences

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 risks and benefits of hydration options and discuss these with the dying person and those important to them, and capture their wishes and preferences.

Healthcare professionals (such as secondary care doctors, nurses, GPs, hospice doctors and district nurses) assess the hydration status of adults in the last days of life daily, including observations for signs and symptoms of overhydration and dehydration. They also discuss options for hydration, explaining the risks and benefits with the person who is dying and those important to them, and identify their wishes and preferences.

Commissioners use contractual and service specification arrangements to ensure that providers assess the hydration needs of adults in the last days of life daily, discuss the risks and benefits of hydration options with the dying person and those important to them, and facilitate the provision of clinically assisted hydration in hospital and community settings.

Adults who are in the last days of life are checked every day to see if they are having problems with hydration. The different choices for hydration, such as having help to keep drinking or having fluids provided through a drip or tube, are explained, along with their risks and benefits. The person is asked which option they would prefer if they have problems staying hydrated.

Source guidance

Care of dying adults in the last days of life. NICE guideline NG31 (2015), recommendations 1.4.1, 1.4.4 and 1.4.5

Definitions of terms used in this quality statement

Hydration status assessed

A clinical review to check for signs of dehydration (such as dry mouth, thirst, confusion and agitation) or overhydration (such as swelling and fluid overload), which could be carried out by a nurse or doctor. This would include objective and subjective measures (for example, hydration of oral mucosa, skin turgor, evidence of peripheral oedema or pulmonary congestion). Blood tests would not routinely form part of the assessment. However, if laboratory test results are present then they may form part of the assessment. Assessment occurs at least daily, but more frequent assessment may be needed because a person's condition can change quickly. [Adapted from NICE's full guideline on care of dying adults in the last days of life and expert opinion]

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 professionals 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.

Update information

Minor changes since publication

November 2024: National data sources used for quality measures have been updated throughout.

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 our webpage on quality standards advisory committees for details about our standing committees. Information about the topic experts invited to join the standing members is available from the webpage for this quality standard.

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 guidance and quality standards apply in England and Wales. Decisions on how they apply in Scotland and Northern Ireland are made by the Scottish government and Northern Ireland Executive. NICE quality standards may include references to organisations or people responsible for commissioning or providing care that may be relevant only to England.

Diversity, equality and language

Equality issues were considered during development and equality assessment for this quality standard 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: 978-1-4731-2373-1

Endorsing organisation

This quality standard has been endorsed by NHS England, as required by the Health and Social Care Act (2012)

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.

- Association for Palliative Medicine of Great Britain and Ireland
- British Geriatrics Society
- National Council for Palliative Care
- Royal College of Physicians (RCP)
- Association of Supportive and Palliative Care Pharmacy
- Royal College of Physicians and Surgeons of Glasgow
- Royal College of Nursing (RCN)
- The Society of Tissue Viability
- Royal College of Anaesthetists