

# End of life care for adults

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## Introduction and overview

This quality standard covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. This includes adults who die suddenly or after a very brief illness. The quality standard does not cover condition-specific management and care, clinical management of specific physical symptoms or emergency planning and mass casualty incidents.

It sets out markers of high-quality care for adults aged 18 years and older with advanced, progressive, incurable conditions; adults who may die within 12 months; and those with life-threatening acute conditions. It also covers support for the families and carers of people in these groups.

It is not expected that each quality statement will apply to all groups. Similarly, some quality statements may need special consideration when applied to certain groups. For example, people with dementia may need to participate in advance care planning significantly earlier in the pathway than people with cancer.

## Introduction

Approximately 500,000 people die in England each year. People with advanced life-threatening illnesses and their families should expect good end of life care, whatever the cause of their condition.

In addition to physical symptoms such as pain, breathlessness, nausea and increasing fatigue, people who are approaching the end of life may also experience anxiety, depression, social and spiritual difficulties. The proper management of these issues requires effective and collaborative, multidisciplinary working within and between generalist and specialist teams,

whether the person is at home, in hospital or elsewhere. Information about people approaching the end of life, and about their needs and preferences, is not always captured or shared effectively between different services involved in their care, including out of hours and ambulance services.

Families, including children, close friends and informal carers, also experience a range of problems at this time. They play a crucial role and have needs of their own before, during and after the person's death: these too must be addressed.

Many people receive high-quality care in hospitals, hospices, care homes and in their own homes but a considerable number do not. Up to 74% of people say they would prefer to die at home ([National Audit Office. End of life care report](#), 2008), but a 2010 report showed that 58% of people die in hospital ([National End of Life Intelligence Network. Variations in place of death in England](#), 2010). There is considerable geographical variation.

This quality standard provides health and social care workers, managers, service users and commissioners with a description of what high-quality end of life care looks like, regardless of the underlying condition or setting. Delivered collectively, these quality statements should contribute to improving the effectiveness, safety and experience of people approaching the end of life, and their families.

This quality standard describes high-quality care that, when delivered collectively, should contribute to improving the effectiveness, safety and experience of care for adults approaching the end of life and the experience of their families and carers. This will be done in the following ways, regardless of condition or setting:

- Enhancing quality of life for people with long-term conditions.
- Ensuring that people have a positive experience of (health) care.
- Treating and caring for people in a safe environment and protecting them from avoidable (healthcare-related) harm.

See the [Department of Health and Social Care's NHS outcomes framework](#).

The quality standard is also expected to contribute to the following overarching outcome(s) for people approaching the end of life:

- The care that people approaching the end of life receive is aligned to their needs and preferences.
- Increased length of time spent in preferred place of care during the last year of life.
- Reduction in unscheduled care hospital admissions leading to death in hospital (where death in hospital is against their stated preference).
- Reduction in deaths in inappropriate places such as on a trolley in hospital or in transit in an ambulance.
- In addition, this quality standard should contribute to:
  - Enhancing quality of life for people with care and support needs.
  - Delaying and reducing the need for care and support.
  - Ensuring that people have a positive experience of (social) care and support.
  - Safeguarding adults whose circumstances make them vulnerable and protecting them from avoidable harm.

See the [Department of Health and Social Care's adult social care outcomes framework](#).

It is important that the quality standard is considered by commissioners, health and social care professionals and patients alongside current policy and guidance documents listed in the evidence sources section, including: the [Department of Health's End of life care strategy: promoting high quality care for all adults at the end of life](#) (2008) and [End of life care strategy: quality markers and measures for end of life care](#) (2009).

## **Overview**

The quality standard for end of life care for adults requires that services are commissioned from and coordinated across all relevant agencies, including specialist palliative care, and encompass the whole end-of-life care pathway. An integrated approach to provision of services is fundamental to the delivery

of high-quality care to people approaching the end of life and their families and carers.

This quality standard uses the following definition of people approaching the end of life from the [General Medical Council's guidance on treatment and care towards the end of life](#): People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with:

- advanced, progressive, incurable conditions
- general frailty and coexisting conditions that mean they are expected to die within 12 months
- existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- life-threatening acute conditions caused by sudden catastrophic events.

Given this, any palliative care within the last 12 months of life is regarded as end of life care. It is recognised that some people will benefit from palliative care before this time. Palliative care before the last 12 months of life is not included in this definition of end of life care and is therefore outside the scope of this quality standard.

Providing end of life care should be an integral part of every health and social care worker's role. However for many, such care is likely to form only a small part of their workload. Many of these professionals are 'generalists' (GPs, community nurses and hospital medical and surgical staff, for example), recognising that some generalists will have a greater role in providing end of life care than others (such as care home workers). Palliative medicine is a recognised medical specialty, requiring the equivalent of 4 years' specialist training. Other specialists will have received specific training and qualifications relating to end of life care, or acquired substantial practical experience. These specialists, who frequently dedicate all or most of their time to the care of people approaching the end of life, include:

- palliative medicine physicians

- palliative care specialist nurses
- specialist allied health professionals
- specialist social workers
- counsellors and therapists.

NICE quality standards are for use by the NHS in England and do not have formal status in the social care sector. However, the NHS will not be able to provide a comprehensive service for all without working with social care communities. In this quality standard, care has been taken to make sure that any quality statements that refer to the social care sector are relevant and evidence-based. Social care commissioners and providers may therefore wish to use them, both to improve the quality of their services and support their colleagues in the NHS.

Subject to legislation currently before Parliament, NICE will be given a brief to produce quality standards for social care. These standards will link with corresponding topics published for the NHS. They will be developed in full consultation with the social care sector and will be presented and disseminated in ways that meet the needs of the social care community. As we develop this library of social care standards, we will review and adapt any published NICE quality standards for the NHS that make reference to social care.

## **List of statements**

[Statement 1](#) People approaching the end of life are identified in a timely way.

[Statement 2](#) People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

[Statement 3](#) People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

[Statement 4](#) People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

[Statement 5](#) People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

[Statement 6](#) People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

[Statement 7](#) Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

[Statement 8](#) People approaching the end of life receive consistent care that is coordinated effectively across all relevant settings and services at any time of day or night, and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

[Statement 9](#) People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

[Statement 10](#) People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

[Statement 11](#) This statement has been removed and replaced by [NICE's quality standard on care of dying adults in the last days of life](#). For more details see [update information](#).

[Statement 12](#) This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

[Statement 13](#) This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

[Statement 14](#) People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

[Statement 15](#) Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

[Statement 16](#) This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

In addition, quality standards that should also be considered when commissioning and providing an end of life care service are listed in [related NICE quality standards](#).

# Quality statement 1: Identification

## Quality statement

People approaching the end of life are identified in a timely way.

## Quality measures

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

## Structure

- a) Evidence of local systems in place to document identification of people approaching the end of life.
- b) Evidence of local retrospective audits of how soon (such as by days, weeks, months or years) people were identified as approaching the end of life before death.

A proportion of deaths will be unexpected and therefore unlikely to be identified in time to be included on a register or equivalent system. Some people may not wish to be identified and/or may not consent to being included on a register or equivalent system.

## Outcome

- a) People approaching the end of life, and their families and carers, are aware of the aims of care.
- b) People approaching the end of life, and their families and carers, feel that early identification of their need for end of life care helped with meeting their specific needs and preferences in a timely and meaningful way.

See the [overview section](#) for overarching outcomes.



## What the quality statement means for each audience

**Service providers** ensure that systems are in place to identify people approaching the end of life in a timely way.

**Health and social care professionals** act to identify people approaching the end of life in a timely way.

**Commissioners** ensure they commission services that identify people approaching the end of life in a timely way and have the capability to record identification.

**People approaching the end of their life** are identified at the right time to receive care and support to meet their needs and preferences.

## Source guidance

[End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.1.1

## Data source

### Structure

- a) [Quality and Outcomes Framework \(QOF\) indicator PC 3](#) (primary care only)
  - the practice has a complete register available of all patients in need of palliative care/support irrespective of age. The draft End of life care locality register pilot programme core dataset from the Information Standards Board records patients in any setting who have been entered onto an end of life care locality register. The draft comprehensive dataset also records the date added to GP Gold Standards Framework register.
- b) Local data collection. The [National End of Life Care Intelligence Network's report, Predicting death: estimating the proportion of deaths that are 'unexpected'](#) is based on Office for National Statistics (ONS) mortality data, which may be useful in estimating the proportion of people who might be identified as approaching the end of life.

## Outcome

a) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on whether the person who died knew that they were likely to die.

b) Local data collection.

## Definitions

Identification of people approaching the end of life may be initiated by either health or social care professionals in any setting. Although professionals should discuss with the person and their families and carers the benefits of being identified and the use of a register or equivalent system, the process of identification should be sensitive to the possibility that not all people will want to be identified and/or placed on a register.

In the [General Medical Council's guidance on treatment and care towards the end of life](#), end of life is defined as when a person is likely to die within the next 12 months. This timeframe provides a guide as to when people might be identified as approaching the end of life. For some conditions, the trajectory may require identification and subsequent planning to happen earlier. For other conditions, it may not be possible to identify people until nearer the time of death. Identification should take place with sufficient time to enable provision of high-quality end of life planning, care and support in accordance with the person's needs and preferences. Identification will need to be considered on an individual basis.

Examples of available tools for assisting clinicians with timely identification of people approaching the end of life, include:

- [Gold Standards Framework prognostic indicator guidance](#)
- [Supportive and Palliative Care Indicators tool from NHS Scotland](#)

See also supporting information on [QOF indicator PC 3](#), which includes examples of identification criteria.

## Quality statement 2: Communication and information

### Quality statement

People approaching the end of life and their families and carers are communicated with, and offered information, in an accessible and sensitive way in response to their needs and preferences.

### Quality measures

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### Structure

- a) Evidence of local availability of end of life care information in a variety of formats and languages.
- b) Evidence of local arrangements for the use of suitable environments to ensure sensitive communication about end of life care.
- c) Evidence of local arrangements to ensure that people approaching the end of life and their families and carers know who to contact for advice.
- d) Evidence that local service user feedback relating to end of life care, in the form of surveys, compliments and complaints, is collected, analysed and acted upon.

### Process

Proportion of people identified as approaching the end of life who are offered information appropriate to their circumstances.

Numerator – the number of people in the denominator offered information appropriate to their circumstances.

Denominator – the number of people identified as approaching the end of life.

## Outcome

- a) People approaching the end of life and their families and carers feel satisfied with how they are communicated with.
- b) People approaching the end of life and their families and carers feel sufficiently informed about what they wish to know and supported to make decisions about their care.

See the [overview section](#) for overarching outcomes.

## What the quality statement means for each audience

**Service providers** ensure that systems are in place to communicate with, and offer information to, people approaching the end of life and their families and carers, in an accessible and sensitive way, in response to their needs and preferences.

**Health and social care workers** communicate with, and offer information to, people approaching the end of life and their families and carers, in an accessible and sensitive way, in response to their needs and preferences.

**Commissioners** ensure they commission services with systems in place to communicate with, and offer information to, people approaching the end of life and their families and carers, in an accessible and sensitive way, in response to their needs and preferences.

**People approaching the end of life and their families and carers** are communicated with and offered information in a sensitive way, at a time when it is helpful and with respect for their needs and preferences.

## Source guidance

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.3.1, 1.4.1 and 1.4.3
- [Improving supportive and palliative care for adults with cancer. NICE cancer service guidance CSG4](#), key recommendation 8 and recommendations 1.25, 2.14, 3.17 and 4.7

## Data source

### Structure

- a) Local data collection. The National care of the dying audit – hospitals may be relevant.
- b) Local data collection. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) whether they were given enough privacy when discussing their condition or treatment.
- c) Local data collection. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) whether hospital staff told them who to contact if they were worried about their condition or treatment after they left hospital.
- d) Local data collection.

### Process

Local data collection. The National care of the dying audit – hospitals may be relevant. [2011/12 Adult Social Care Outcome Framework](#): 3D: the proportion of people who use services and carers who find it easy to find information about services. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) how much information about their condition or treatment was given to them.

### Outcome

- a) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on whether the person who has died was told they were likely to die in a sensitive and caring way. The NHS inpatient services survey asks inpatients (not specific to end of life care) whether they were given enough privacy when discussing their condition or treatment.
- b) Local data collection. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) whether they got answers they could understand when they had important questions to ask a doctor or nurse;

whether their family or someone else close to them had enough opportunity to talk to a doctor if they wanted to and whether doctors or nurses gave their family or someone close to them all the information they needed to help care for them.

## **Definitions**

Communication and information should be appropriate to the stage reached by the person who is approaching the end of life, and at a time (not too early or too late) when information is requested or useful in order to make choices or decisions. Communication with, and information for, families and carers should be considered around the same time as with the person approaching the end of life.

'Responsive' communication and information provision recognises that communication is a two-way process and that people's circumstances are likely to change over time. It is also tailored to individual circumstances, such as recognising the different needs of children and young people compared with adults.

Information offered to people approaching the end of life, and their families and carers, should include:

- information about treatment and care options, medication and what to expect at each stage of the journey towards the end of life
- who they can contact at any time of day or night to obtain advice, support or services
- practical advice and details of other relevant services such as benefits support
- details of relevant local and national self-help and support groups.

All information should be available in a variety of accessible formats and free at the point of delivery. Examples of leaflets on end of life care include those available to download from the [Dying Matters Coalition](#). Examples of information resources available specifically for children and young people

include those from the [Palliative Care Institute Liverpool](#) and the [Childhood Bereavement Network](#).

All communication and information provision should be sensitive to the needs and preferences of the person approaching the end of life and their families and carers, including those who do not wish to have such conversations at the present time. Those who do not wish to have information should have their preferences respected.

## **Quality statement 3: Assessment, care planning and review**

### **Quality statement**

People approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### **Process**

Proportion of people identified as approaching the end of life whose records include a documented assessment and discussion of their physical, psychological, social, spiritual and cultural needs and preferences.

Numerator – the number of people in the denominator whose records include a documented assessment and discussion of their physical, psychological, social, spiritual and cultural needs and preferences.

Denominator – the number of people identified as approaching the end of life.

## **Outcome**

a) People approaching the end of life and their families and carers feel that the assessment process was a useful means to considering their needs and preferences, identifying next steps and securing appropriate services.

b) People approaching the end of life feel satisfied that they have been able to discuss, record and review their needs and preferences if they would like to do so.

See the [overview section](#) for overarching outcomes.

## **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to ensure comprehensive holistic assessments are carried out with people identified as approaching the end of life, in response to their changing needs and preferences, with the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

**Health and social care professionals** offer or contribute to comprehensive holistic assessments with people identified as approaching the end of life, in response to their changing needs and preferences, including giving them the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

**Commissioners** ensure they commission services that carry out comprehensive holistic assessments with people identified as approaching the end of life, in response to their changing needs and preferences, which include the opportunity to discuss, develop and review a personalised care plan for current and future support and treatment.

**People approaching the end of life** are offered full assessments to ensure they are getting the best care and support for their circumstances. During these assessments, they have the opportunity to discuss their needs (for example, physical, psychological, social, spiritual and cultural needs) and preferences. This includes the opportunity to develop and review a care plan detailing their preferences for current and future support and treatment.



## Source guidance

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.2.1, 1.5.3 and 1.7.1

## Data source

### Process

Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes questions on whether the person who has died was involved in decisions about their care and whether healthcare staff had a record of where the person would have liked to have died. The National care of the dying audit – hospitals may be relevant. The draft End of life care locality register pilot programme core dataset from the Information Standards Board includes preferences such as who else the person would like involved in decisions, preferences for place of death, ‘do not attempt cardiopulmonary resuscitation’ (DNACPR) request, Legal Advance Decision treatment refusal documents and details of any identified Lasting Power of Attorney. The comprehensive dataset also records religion or spiritual beliefs, whether the person has any special requests or preferences, whether there is anything in particular that they wish (ideally) to avoid, whether resuscitation has been discussed with them or their family and whether they have expressed a wish for organ or tissue donation.

### Outcome

a) and b) Local data collection.

## Definitions

A ‘holistic’ assessment includes, as a minimum, physical, psychological, social, spiritual, cultural, and where appropriate, environmental considerations. This may relate to needs and preferences as well as associated treatment, care and support.

Personalised care plans may also be known as personalised ‘support’ plans.

A comprehensive assessment is likely to be multidisciplinary and may require the input of both health and social care professionals, as well as other appropriate support services. A comprehensive assessment is one that is coordinated effectively in order to avoid duplication.

All assessments and related care planning should be carried out in a sensitive way and in the best interests of the person approaching the end of life, with appropriate consent. Discussion about the value of the assessment process and what the person and their families and carers can expect should be offered.

The following description of assessment is adapted from [NICE's guideline on improving supportive and palliative care for adults with cancer](#):

Assessments should encompass all aspects of end of life care, taking into account the preferences of the person approaching the end of life, and their families and carers, with respect to:

- written and other forms of information
- face-to-face communication
- involvement in decision-making
- control of physical symptoms
- psychological support
- social support
- spiritual support
- organ and tissue donation.

Once people have been identified as approaching the end of life, they should receive a prompt initial holistic assessment. Assessment should be an ongoing and proactive process that is both planned and responsive. Timing of assessments should take into account changes in the person's condition or circumstances as well as specific requests from the person approaching the end of life and their families and carers.

[Holistic common assessment guidance from the National End of Life Care Programme](#) provides information on assessment during the last year of life.

Information about personalised care plans, which may or may not include advance statements or advance decisions to refuse treatment depending on the person's preferences, is available from the [National End of Life Care Programme's Capacity, care planning and advance care planning in life limiting illness: A guide for health and social care staff](#).

A [Department of Health guide to person-centred care planning in adult social care](#) is also available.

## **Quality statement 4: Holistic support – physical and psychological**

### **Quality statement**

People approaching the end of life have their physical and specific psychological needs safely, effectively and appropriately met at any time of day or night, including access to medicines and equipment.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### **Structure**

- a) Evidence of local arrangements to provide people approaching the end of life with access to psychological support.
  
- b) Evidence of local use of supportive environments for managing psychological symptoms in people approaching the end of life that provide privacy and dignity.

## **Process**

a) Proportion of people identified as approaching the end of life who have a treatment plan for symptom management incorporating current and anticipated physical and specific psychological needs.

Numerator – the number of people in the denominator with a treatment plan for current and future symptom management incorporating physical and specific psychological needs.

Denominator – the number of people identified as approaching the end of life.

b) Proportion of people identified as approaching the end of life with unrelieved physical symptoms who are referred for specialist palliative care advice.

Numerator – the number of people in the denominator referred for specialist palliative care advice.

Denominator – the number of people identified as approaching the end of life with unrelieved physical symptoms.

c) Proportion of people identified as approaching the end of life with unrelieved specific psychological symptoms who are referred for specialist psychological advice.

Numerator – the number of people in the denominator referred for specialist psychological advice.

Denominator – the number of people identified as approaching the end of life with unrelieved specific psychological symptoms.

## **Outcome**

a) People approaching the end of life feel satisfied with their level of physical comfort.

b) People approaching the end of life feel psychologically supported.

c) Carers and families of people approaching the end of life feel satisfied with the management of the person's physical comfort and psychological support, where appropriate.

See the [overview section](#) for overarching outcomes.

## **What the quality statement means for each audience**

**Service providers** ensure that services are available and systems are in place to meet the physical and specific psychological needs of people approaching the end of life, including access to medicines and equipment, in a safe, effective and appropriate way at any time of day or night.

**Health and social care professionals** manage physical and specific psychological symptoms in people approaching the end of life, including provision of medicines and equipment, in a safe, effective and appropriate way at any time of day or night. This may include contacting specialists for advice.

**Commissioners** ensure they commission generalist and specialist services that are able to meet the physical and specific psychological needs of people approaching the end of life, including access to medicines and equipment, in a safe, effective and appropriate way at any time of day or night.

**People approaching the end of life** receive treatment and care to manage their physical and psychological needs, which may be at any time of day and night.

## **Source guidance**

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendations 1.9.1, 1.9.2 and 1.12.1

## **Data source**

### **Structure**

a) Local data collection.: various measures relating to psychological support for people with cancer (no national data collection).

b) Local data collection. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) whether they were given enough privacy when discussing their condition or treatment.

## **Process**

a) Local data collection.

b) Local data collection. The draft End of life care locality register pilot programme comprehensive dataset from the Information Standards Board records whether the person is known to a specialist palliative care team.

c) Local data collection.

## **Outcome**

a) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes questions on how well the person's pain was relieved. The National care of the dying audit – hospitals may be relevant. The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) whether they were ever in any pain and whether they thought that hospital staff did everything they could to help control their pain.

b) Local data collection.

c) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on the level of support provided for relief of pain and other symptoms.

## **Definitions**

It is recognised that physical and psychological symptoms cannot always be fully controlled. Effective symptom management results in the optimum comfort level that can be achieved for the person approaching the end of life, within clinical possibility and limitations, and patient choice. All treatment and support should be tailored to the individual.

The treatment plan for managing symptoms and side effects should be recorded in a personalised care plan described in quality statement 3.

Safe, effective and appropriate symptom and side-effect management at any time of day or night may require coordinated input from a number of different professionals and services. As a minimum, essential 24/7 care services should include:

- generalist medical services (including GPs)
- nursing services (defined as visiting, rapid response services and provision of one-to-one care at home, including overnight)
- personal care services
- access to pharmacy services
- access to equipment and adaptations
- specialist palliative care advice for generalists on symptom and side-effect management.

Psychological support encompasses general emotional support and empowerment as well as specialist psychological care. Emotional support is covered in quality statements 5 and 14. Specific psychological needs are more likely to require psychological interventions beyond the general emotional support that most people will need. Psychological interventions may include, but are not limited to, cognitive behaviour therapy, social skills training, work with phobias and confidence issues, and medication to ease psychological distress, including anxiety and depression.

Timescales for addressing symptoms and side effects will depend on the individual symptom, comfort and preferences of the person approaching the end of life and should be determined by clinical judgment. Response times should be independent of care setting.

Appropriate steps should be taken to alleviate symptoms in all circumstances, including where the person approaching the end of life is unable to communicate.

## **Quality statement 5: Holistic support – social, practical and emotional**

### **Quality statement**

People approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

### **Quality measures**

#### **Structure**

Evidence of local arrangements to ensure that people approaching the end of life are offered timely personalised support for their social, practical and emotional needs, which is appropriate to their preferences, and maximises independence and social participation for as long as possible.

#### **Process**

a) Proportion of people identified as approaching the end of life who receive information on social, practical and emotional support available.

Numerator – the number of people in the denominator receiving information on social, practical and emotional support available.

Denominator – the number of people identified as approaching the end of life.

b) Proportion of people identified as approaching the end of life who receive social and practical support in accordance with their care plan.

Numerator – the number of people in the denominator receiving social and practical support in accordance with their care plan.

Denominator – the number of people identified as approaching the end of life.



## **Outcome**

- a) People approaching the end of life feel supported to live independently, in accordance with their preferences, for as long as possible.
- b) People approaching the end of life feel able to maintain social participation, in accordance with their preferences, for as long as possible.
- c) People approaching the end of life feel emotionally supported.

See the [overview section](#) for overarching outcomes.

## **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to provide timely personalised support to people approaching the end of life for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible.

**Health and social care workers** follow local policies and procedures and signpost to relevant national or local services, to ensure that people approaching the end of life are offered timely personalised support for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible.

**Commissioners** ensure they commission services that provide timely personalised support to people approaching the end of life for their social, practical and emotional needs. Support should be appropriate to their preferences, and maximise independence and social participation for as long as possible.

**People approaching the end of life** are offered social, practical and emotional support tailored to their needs and at the right time to help them feel supported, retain their independence and do things they enjoy for as long as possible.

## Source guidance

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.2.1, 1.8.1 and 1.9.1

## Data source

### Structure

Local data collection. [National cancer peer review programme: Manual for cancer services: rehabilitation measures](#) – various measures relating to rehabilitation for people with cancer (no national data collection).

### Process

a) Local data collection. [2011/12 Adult Social Care Outcome Framework](#): 3D: the proportion of people who use services and carers who find it easy to find information about services.

b) Local data collection.

### Outcome

a) and b) Local data collection. [Transparency in outcomes: a framework for quality in adult social care – The 2011/12 adult social care outcomes framework](#) indicator 1B: the proportion of people who use services who have control over their daily life.

c) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on the level of emotional support provided in the last 2 days of life.

## Definitions

The definition of 'timely' will depend on the type of need and individual circumstances.

The [Department of Health](#) defines social care as a wide spectrum of activities that support and help people live their daily lives. It can include: intimate personal care, managing finances, adapting housing conditions, help attending leisure pursuits and support for carers.

Social support should include, but is not limited to (adapted from [NICE's cancer service guidance on improving supportive and palliative care for adults with cancer](#)):

- Assistance to obtain financial support, including information about 'special rules' or equivalent, and access to individuals such as welfare rights and benefits advisers who can provide information and assistance in completing applications.
- Support with legal and practical affairs such as wills and funeral arrangements.
- Practical support and advice, including personal and domestic care.
- Support, advice and therapy to maintain independent living, including home adaptations and the provision of equipment.
- Services to assess the needs and protect the rights of vulnerable adults or children of a family member approaching the end of life, and to support people approaching the end of life in caring for vulnerable adults or children.
- Respite and day care/therapy in social and health care settings.
- Care home placements.

Support for social needs may or may not require social care services. For example, many people rely on families and friends and their community to meet their social needs. Some voluntary organisations provide support services for people approaching the end of life.

Further information on community-based support is available from [Think local act personal](#).

National eligibility criteria for adult social care is available in the [Department of Health's guidance on eligibility criteria for adult social care, England 2010](#).

The [Social Care Institute for Excellence web pages on end of life care](#) provide a place where new and existing information, resources and links are gathered together to support social care practitioners working with people and their families at the end of life.

Practical support should be provided by a multidisciplinary team, which may include occupational therapists, physiotherapists and other health professionals employed by health services, in addition to social care services. Effective practical support will require timely and rapid access to appropriate equipment such as commodes, pressure-relieving mattresses and other aids, to meet individual needs and preferences.

A stepped approach to emotional support may be appropriate, which could include but is not limited to:

- information about local support services
- general emotional support, such as supportive conversations with generalist health and social care workers or support from the voluntary, community and faith sectors
- referral to more specialist support from trained counsellors, mental health workers or specialists in palliative care.

It is recognised that conflict can arise between what professionals may deem appropriate and what the person approaching the end of life wants or prefers, which may also differ with the views of families and carers. Appropriate support is support that has due regard to the preferences of the person approaching the end of life and is in their best interests.

## **Quality statement 6: Holistic support – spiritual and religious**

### **Quality statement**

People approaching the end of life are offered spiritual and religious support appropriate to their needs and preferences.

### **Quality measures**

#### **Structure**

- a) Evidence of local access to a range of spiritual care providers for people approaching the end of life, either in-house or through referral to appropriate providers in the community.
- b) Evidence of availability of local chaplaincy services in accordance with the [Department of Health's NHS chaplaincy: meeting the religious and spiritual needs of patients and staff](#) (2003).

#### **Process**

Proportion of people identified as approaching the end of life who receive spiritual and religious support in accordance with their care plan.

Numerator – the number of people in the denominator receiving spiritual and religious support in accordance with their care plan.

Denominator – the number of people identified as approaching the end of life.

#### **Outcome**

People approaching the end of life feel satisfied with the spiritual and/or religious support they have been offered and/or received.

See the [overview section](#) for overarching outcomes.

### **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to

people approaching the end of life that is appropriate to the person's needs and preferences.

**Health and social care workers** offer, facilitate and provide (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to the person's needs and preferences.

**Commissioners** ensure they commission services with adequate provision for offering, facilitating and providing (including sign-posting and referral) spiritual and religious support to people approaching the end of life that is appropriate to person's needs and preferences.

**People approaching the end of life** are offered spiritual and/or religious support appropriate to their needs and preferences.

## **Source guidance**

[End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.2.1 and 1.9.2

## **Data source**

### **Structure**

- a) Local data collection.
- b) Local data collection.
- c) Local data collection.

### **Process**

Local data collection.

### **Outcome**

Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on the level of spiritual support provided in the last 2 days of life.

## Definitions

In the context of the draft Spiritual support and bereavement care quality markers, spirituality is defined as ‘those beliefs, values and practices that relate to the human search for meaning in life. For some people, spirituality is expressed through adherence to an organised religion, while for others it may relate to their personal identities, relationships with others, secular ethical values or humanist philosophies’.

In [Standards for NHS Scotland Chaplaincy Services 2007](#) spiritual and religious care are defined as follows: ‘religious care is given in the context of shared religious beliefs, values, liturgies and lifestyle of a faith community. Spiritual care is usually given in a one to one relationship, is completely person centred and makes no assumptions about personal conviction of life orientation. Spiritual care is not necessarily religious. Religious care, at its best is always spiritual’.

Spiritual support helps people approaching the end of life and those close to them including their relatives, carers and friends, to:

- explore how they might understand, make sense of or find meaning in what is happening to them
- identify sources of strength they can draw on, and
- decide whether those sources are helpful during this period in their lives.

Such support does not have to be structured, but the expectation is that it would also include assessment and provision of resources to support the person approaching the end of life and those close to them. Spiritual support is tailored to the needs, beliefs and values of the person approaching the end of life.

Within healthcare, chaplains are the main spiritual care providers. In some circumstances, health and social care professionals and workers may assist with spiritual care. Spiritual interventions that make up spiritual support can come in many forms, such as:

- referral to a chaplain or dedicated spiritual care provider, counsellor, psychologist or therapist, or where appropriate a spiritual leader in the community
- arranging transport so that a person can attend religious services in places of faith and worship
- counselling someone who feels that life has lost all meaning, listening to them express doubts about their religious faith, or helping them make peace with their family or their own past.

Families and relationships tend to be an important influence on spiritual wellbeing, and much support can be provided from within the family or by close friends.

The [General Medical Council's guidance on personal beliefs and medical practice](#) (2013) provides detailed guidance for doctors on personal beliefs.

Further detail on auditing spiritual support is available from draft Spiritual support and bereavement care quality markers and measures for end of life care (NHS National End of Life Care Programme 2011).

## **Quality statement 7: Holistic support – families and carers**

### **Quality statement**

Families and carers of people approaching the end of life are offered comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.



## **Structure**

a) Evidence of local arrangements to ensure that families and carers of people approaching the end of life receive comprehensive holistic assessments in response to their changing needs and preferences.

b) Evidence of local arrangements to ensure that families and carers of people approaching the end of life are offered holistic support appropriate to their own current needs and preferences.

## **Process**

a) Proportion of nominated informal carers (such as a family member) of people identified as approaching the end of life, who receive a comprehensive and holistic assessment of their own needs and preferences.

Numerator – the number of people in the denominator receiving a comprehensive and holistic assessment of their own needs and preferences.

Denominator – the number of nominated informal carers (such as a family member) of people identified as approaching the end of life.

b) Proportion of nominated informal carers (such as a family member) of people identified as approaching the end of life, who receive holistic support in accordance with their most recent assessment.

Numerator – the number of people in the denominator receiving holistic support in accordance with their most recent assessment.

Denominator – the number of nominated informal carers (such as a family member) of people identified as approaching the end of life, who have received an assessment of their own needs.

## **Outcome**

a) Carers and families of people approaching the end of life feel supported.

b) Carer quality of life.

See the [overview section](#) for overarching outcomes.

## **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to offer families and carers of people approaching the end of life comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

**Health and social care professionals** offer families and carers of people approaching the end of life comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

**Commissioners** ensure they commission services that offer comprehensive holistic assessments in response to their changing needs and preferences, and holistic support appropriate to their current needs and preferences.

**Families and carers of people approaching the end of life** have their own needs fully assessed as appropriate for their changing needs and preferences, and are offered support to help them cope.

## **Source guidance**

[Supporting adult carers. NICE guideline NG150](#) (2020), recommendations 1.3.2 and 1.3.4

[End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.3.1

## **Data source**

### **Structure**

a) [Quality and Outcomes Framework \(QOF\) indicator MANAGEMENT 9](#) (primary care): The practice has a protocol for the identification of carers and a mechanism for the referral of carers for social services assessment. The [Operating Framework for the NHS in England 2011–12](#) integrated performance measure SQU08: Agree and make available to local people policies, plans and budgets to support carers (not specific to end of life care).

b) Local data collection.

### **Process**

a) Local data collection. The draft End of life care locality register pilot programme core dataset from the Information Standards Board records carer details. The draft comprehensive dataset records whether there is a care plan in place for the carer.

b) Local data collection.

### **Outcome**

a) Local data collection. [2011/12 Adult Social Care Outcome Framework](#) indicators 3B – Overall satisfaction of carers with social services and 3C – The proportion of carers who say that they have been included or consulted in discussions about the person they care for (not end of life care specific). [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes a question on whether the responder and their family got as much help and support from health and social services as they needed when caring for the person who died and whether they were able to discuss any worries and fears they may have had about the person's condition, treatment or tests with GPs.

b) Local data collection. The [NHS Outcomes Framework 2011/12](#) indicator 2.4 – Health-related quality of life for carers (not end of life care specific). [2011/12 Adult Social Care Outcome Framework](#) indicator 1D – Carer-reported quality of life (not end of life care specific).

### **Definitions**

A 'holistic' assessment includes, as a minimum: physical, psychological, social, spiritual, cultural, and where appropriate, environmental considerations. This may relate to needs and preferences as well as associated treatment, care and support.

A comprehensive assessment is likely to be multidisciplinary and may require the input of both health and social care professionals, as well as other

appropriate support services. A comprehensive assessment is one that is coordinated effectively in order to avoid duplication.

'Carers' here are defined as informal, unpaid carers or supporters, rather than paid health and social care workers. Sometimes the main carer will be a child, a young person or a person with his or her own disability, and services should be sensitive to the particular issues that this may raise. Carers can be identified for this assessment by social services, GPs and through self-referral. The term 'families' is broad and relates to any person who has significant contact with the person approaching the end of life, including children, a partner or close friends. Occasionally, particularly in hostels, for example, staff working directly with the person approaching the end of life may fulfil this role.

A carer's assessment is defined by NICE's guideline on supporting adult carers. Anyone who is an unpaid carer for a family member or friend has the right to discuss their own needs with their local authority, separate to the needs of the person they care for. This is a statutory requirement under the Care Act 2014. Carers can discuss anything they think would help with their own health and wellbeing or with managing other aspects of their life, including their caring role. The local authority uses this information to decide what help it can offer.

Support for families and carers may include emotional and psychological support. Training on practical issues should be available for those caring for people approaching the end of life who require extra help with daily living or extensive care. Addressing the needs of carers should also include access to good quality respite care, appropriate to their circumstances. This may include residential and day respite, as well as overnight one-to-one care in the person's home, for example. Support may also encompass planning for other circumstances, for example when carers are taken ill.

The emphasis here is on support being offered to carers. The right of carers to refuse support must be respected. Carers who decline support initially should be offered the opportunity to change their minds later on, if they wish.

Examples of information resources available for families and carers include those from the [Dying Matters Coalition](#).

[Royal College of General Practitioners' Supporting carers: an action guide for general practitioners and their teams](#) is available.

Bereavement support is addressed specifically in [quality statement 14](#).

## Quality statement 8: Coordinated care

### Quality statement

Adults approaching the end of their life receive care that is coordinated between health and social care practitioners within and across different services and organisations. [2011, updated 2021]

### Quality measures

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### Outcome

See the [overview section](#) for overarching outcomes.

### What the quality statement means for each audience

**Service providers** ensure that systems (such as those for information sharing) are in place, to provide consistent care at all times of day and night to people approaching the end of life, that is coordinated effectively across all relevant settings and services and delivered by practitioners who are aware of the person's current medical condition, care plan and preferences.

**Health and social care professionals** provide consistent care for people approaching the end of life at all times of day or night that is coordinated effectively across all relevant settings and services. They follow local policies and procedures for information sharing so that care is delivered by

practitioners who are aware of the person's current medical condition, care plan and preferences.

**Commissioners** ensure they commission services with appropriate systems in place (including those for information sharing) to ensure that people approaching the end of life receive consistent care at all times of day and night, that is coordinated effectively across all relevant settings and services and that is delivered by practitioners who are aware of their current medical condition, care plan and preferences.

**People approaching the end of life** receive care whenever they need it (day or night) that is consistent, smoothly coordinated and delivered by staff who are aware of their medical condition, care plan and preferences.

### Source guidance

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendations 1.8.1 and 1.12.1

### Data source

The following data sources may be relevant to the referenced measures:

[Quality and Outcomes Framework \(QOF\) indicator RECORDS 3](#): The practice has a system for transferring and acting on information about patients seen by other doctors out of hours.

[QOF indicator RECORDS 13](#): There is a system to alert the out-of-hours service or duty doctor to patients dying at home.

[QOF indicator PC 2](#): The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed.

The National care of the dying audit – hospitals may be relevant.

The [NHS adult inpatient services survey](#) asks inpatients (not specific to end of life care) questions about delayed discharge from hospital.

[Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#)

includes questions on whether services worked well together.

The draft End of life care locality register pilot programme core dataset from the Information Standards Board records details of a key worker.

## **Definitions**

Consistent care means that the person approaching the end of life experiences seamless care that is of a uniformly high standard, regardless of which professionals are delivering the care at the time and in what setting. Also, the information that the person receives is clear and the content is neither confusing nor contradictory.

The 'source references' provide detailed examples of what information should be shared, and between which providers and services. Particular attention should be paid to communication between settings and between daytime and out-of-hours services. One mechanism for facilitating effective care coordination could be the implementation of a locality register or equivalent system. Information on the use of locality registers for end of life care is available from the [Ambitions for palliative and end of life care, End of life locality registers evaluation](#), supported by the Department of Health and National End of Life Care Programme. End of life care locality registers are also known as electronic palliative care coordination systems. Standardised documentation may also be helpful.

All information-sharing should be carried out with appropriate consents and in accordance with current confidentiality and data protection guidance.

[Department of Health quality markers and measures for end of life care](#) refer to a 'key worker' as an example of how coordinated care might be facilitated. A key worker is one or possibly a small number of named workers who, with the consent and agreement of the person approaching the end of life, take an important role in coordinating the individual's care. They promote continuity, ensuring the individual, and their families and carers, know who to access for information and advice. Further definition of the key worker role is available

from [NICE's cancer service guidance on improving supportive and palliative care for adults with cancer](#), recommendation 1.29.

Coordination of care is important for ensuring timely, safe and effective transfer of appropriate documentation, patient records, equipment and medication.

## **Quality statement 9: Urgent care**

### **Quality statement**

People approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care appropriate to their needs and preferences.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### **Structure**

Evidence of local arrangements to ensure that people approaching the end of life who experience a crisis at any time of day or night receive prompt, safe and effective urgent care. This should be appropriate to their needs and preferences and delivered within locally agreed timescales.

### **Process**

Proportion of nominated informal carers (such as a family member) of people identified as approaching the end of life, who have information about how to access urgent care in the event of a crisis at any time of day or night.

Numerator – the number of people in the denominator receiving information about how to access urgent care in the event of a crisis at any time of day or night.



Denominator – the number of nominated informal carers (such as a family member) of people identified as approaching the end of life.

### **Outcome**

a) People approaching the end of life feel that any crisis or need for urgent care was addressed in a prompt, safe and effective way appropriate to their needs and preferences.

b) Carers of people approaching the end of life feel that any crisis or need for urgent care was addressed in a prompt, safe and effective way appropriate to the person's needs and preferences.

See the [overview section](#) for overarching outcomes.

### **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to provide people approaching the end of life who experience a crisis at any time of day or night, with prompt, safe and effective urgent care, appropriate to the person's needs and preferences.

**Health and social care professionals** respond appropriately to crises experienced by people approaching the end of life, at any time of day or night, by providing prompt, safe and effective urgent care, appropriate to the person's needs and preferences.

**Commissioners** ensure they commission urgent care services that provide people approaching the end of life who experience a crisis at any time of day or night, with prompt, safe and effective urgent care, appropriate to the person's needs and preferences.

**People approaching the end of life who experience a crisis at any time of day or night** receive prompt, safe and effective urgent care that takes into account their needs and preferences.

## Source guidance

[End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.12.1

## Data source

### Structure

Local data collection.

### Process

Local data collection.

### Outcome

a) Local data collection. The [NHS Outcomes Framework 2011/12](#) indicator 4.3 – patient experience of A&E services (not specific to end of life care).

b) Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes questions on urgent care.

## Definitions

A 'crisis' is a significant unplanned event where there is an element of distress or disruption requiring urgent response and appropriate intervention.

The definition of 'prompt' will vary depending on the circumstances of the crisis. Timescales should be determined locally based on need.

In the [Royal College of General Practitioners' Urgent and emergency care clinical audit toolkit](#), reference is made to a definition of urgent care as the range of responses that health and care services provide to people who require – or who perceive the need for – urgent advice, care, treatment or diagnosis. People using services and their families and carers, should expect 24 hours a day, 7 days a week consistent and rigorous assessment of the urgency of their care need and an appropriate and prompt response to that need.

Urgent care may also be described as unscheduled care and includes, but is not limited to, both daytime and out-of-hours GP visits in the community, as well as emergency 999 ambulance response and rapid access care. Urgent care may be provided by a range of professionals across all settings and is delivered in a number of different forms. Settings may include, but are not limited to, primary, secondary, and community-based services.

Coordinated care with effective information sharing is essential to delivering urgent care that takes into account both the needs and preferences of the person approaching the end of life (see quality statement 8 on coordinated care). There must also be adequate provision of appropriate specialist palliative care advice and staff who are responsive to emergency need, including the option for 24 hours a day, 7 days a week access to specialist palliative inpatient care (see quality statements 4, 10 and 16).

## **Quality statement 10: Specialist palliative care**

### **Quality statement**

People approaching the end of life who may benefit from specialist palliative care, are offered this care in a timely way appropriate to their needs and preferences, at any time of day or night.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### **Outcome**

See the [overview section](#) for overarching outcomes.

### **What the quality statement means for each audience**

**Service providers** ensure that systems are in place (such as shift patterns and on-call rotas), to provide timely specialist palliative care and advice at any

time of day and night for people approaching the end of life who may benefit from specialist input. Care should be appropriate to the person's needs and preferences.

**Health and social care professionals** provide timely specialist palliative care and advice at any time of day or night for people approaching the end of life who may benefit from it, or know who to contact for specialist palliative care and advice. Care should be appropriate to the person's needs and preferences.

**Commissioners** ensure they commission specialist palliative care services with sufficient provision and capacity to provide timely specialist palliative care and advice at any time of day and night for people approaching the end of life who may benefit from specialist input. Care should be appropriate to their needs and preferences.

**People approaching the end of life** are offered specialist palliative care if their usual care team are unable to relieve their symptoms adequately. It is offered at the right time for them and is appropriate to their needs and preferences at any time of day or night.

## **Source guidance**

[End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendation 1.12.1

## **Data source**

### **Process**

Local data collection. The draft End of life care locality register pilot programme comprehensive dataset from the Information Standards Board records whether the person is known to a specialist palliative care team.

Activity data on specialist palliative care services is collected via the [National Council for Palliative Care's minimum data set \(MDS\) for specialist palliative care services](#).

## Definitions

Specialist palliative care encompasses hospice care (including inpatient hospice, day hospice, hospice at home) as well as a range of other specialist advice, support and care such as that provided by hospital palliative care teams. Specialist palliative care should be available on the basis of need, not diagnosis.

'People who may benefit from specialist palliative care' are those whose symptoms cannot be managed in a timely way by their usual care team.

The following minimum recommended service levels have been adapted from [NICE's cancer service guidance on improving supportive and palliative care for adults with cancer](#) and the [Department of Health quality markers](#).

Specialist palliative care inpatient facilities should be responsive to emergency need and able to admit people approaching the end of life at any time of day or night.

Palliative care services should ensure provision to:

- Visit and assess people approaching the end of life face-to-face in any setting between 09.00 and 17.00, 7 days a week (provision for bed-side consultations outside these hours is high-quality care).
- Provide specialist palliative care advice at any time of day or night, which may include telephone advice.

Specialist palliative care, including assessment and advice, may be provided by physicians in palliative medicine or other suitably trained practitioners, such as clinical nurse specialists in palliative care. Qualified district nurses – 'specialist community practitioners in home nursing' – may or may not have an appropriate level of education in specialist palliative care. Social workers, occupational therapists, physiotherapists and other therapists may also have specialist skills in palliative care.

## **Quality statement 11: Care in the last days of life**

This statement has been removed and replaced by [NICE's quality standard on care of dying adults in the last days of life](#). For more details see [update information](#).

## **Quality statement 12: Care after death – care of the body**

This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

## **Quality statement 13: Care after death – verification and certification**

This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

## **Quality statement 14: Care after death – bereavement support**

### **Quality statement**

People closely affected by a death are communicated with in a sensitive way and are offered immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

### **Quality measures**

Measures from the Department of Health's [End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

## Structure

a) Evidence of a local needs assessment for bereavement services, detailing specialist support needs for all sections of the community including vulnerable groups such as children and those with learning difficulties.

b) Evidence that a local service specification for bereavement services has been developed in partnership with acute, community, voluntary and private sector providers and local authorities, which includes the provision of specialist support for groups identified in the needs assessment.

## Outcome

People closely affected by a death feel that information and support was available to them around the time of death and afterwards, which was appropriate for them and offered at the right time.

See the [overview section](#) for overarching outcomes.

## What the quality statement means for each audience

**Service providers** ensure that systems are in place for people closely affected by a death that include sensitive communication and provision for immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

**Health and social care workers** communicate sensitively with people closely affected by a death and offer them immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

**Commissioners** ensure they commission services for people closely affected by a death that include sensitive communication and provision for immediate and ongoing bereavement, emotional and spiritual support appropriate to their needs and preferences.

**People closely affected by a death** are communicated with in a sensitive way and offered bereavement, emotional and spiritual support appropriate to their needs and preferences. This may include information about practical

arrangements and local support services, supportive conversations with staff, and in some cases referral for counselling or more specialist support.

## **Source guidance**

- [Supporting adult carers. NICE guideline NG150](#) (2020), recommendation 1.9.14 and 1.9.15

## **Data source**

### **Structure**

a) Local data collection.

b) Local data collection.

### **Outcome**

Local data collection. [Office for National Statistics \(ONS\) National bereavement survey \(VOICES\)](#) includes questions on whether enough help and support was provided by the healthcare team to the family or carer at the actual time of death, whether staff dealt with them in a sensitive manner, and whether they have since talked to anyone from health and social services or from a bereavement service, about their feelings about the person's illness and death.

## **Definitions**

People closely affected by a death may include care home residents, staff and volunteers, staff from a variety of health and social care organisations, as well as family members and carers, including children. Children may need particular tailored support.

Families and carers of people who have died suddenly or in an unexpected way, as well as those who were expecting the death, should have access to information and support appropriate to their circumstances.

Draft Spiritual support and bereavement care quality marker 2 on bereavement support recommends that bereaved people are offered support



at the time of death that is culturally and spiritually appropriate, immediate, and available shortly afterwards.

Bereavement support may be not be limited to immediately after death, but may be required on a longer-term basis and, in some cases, may begin before death.

A stepped approach to emotional and bereavement support may be appropriate, which could include but is not limited to:

- information about local support services
- practical support such as advice on arranging a funeral, information on who to inform of a death, help with contacting other family members and information on what to do with equipment and medication
- general emotional and bereavement support, such as supportive conversations with generalist health and social care workers or support from the voluntary, community and faith sectors
- referral to more specialist support from trained bereavement counsellors or mental health workers.

See quality statement 6 for a definition of spiritual support.

A model of bereavement support is detailed in [NICE's cancer service guidance on improving supportive and palliative care for adults with cancer](#), recommendation 12.30.

People closely affected by a death should be able to access all support within an appropriate physical environment that facilitates sensitive communication.

## **Quality statement 15: Workforce – training**

### **Quality statement**

Health and social care workers have the knowledge, skills and attitudes necessary to be competent to provide high-quality care and support for people approaching the end of life and their families and carers.

### **Quality measures**

Measures from the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009).

See also the [section on quality measures and national indicators](#) for further information.

### **Structure**

- a) Evidence of local arrangements to ensure that health and social care workers receive training appropriate to their role incorporating dealing with loss, grief and bereavement, and basic aspects of spiritual care, common to people of all faiths and none.
- b) Evidence of local arrangements to ensure that training is informed by current legislation, national competencies and good practice guidelines, where available.
- c) Evidence of local arrangements to ensure that training is followed up with the use of competences as part of appraisals and professional development plans for health and social care workers to ensure that appropriate knowledge, skills and attitudes are embedded into practice and kept up to date.

### **Outcome**

- a) Improved patient safety relating to end of life care treatment.
- b) Health and social care workers who come into contact with people approaching the end of life and/or their families and carers feel confident and supported in caring for this group.

See the [overview section](#) for overarching outcomes.

## **What the quality statement means for each audience**

**Service providers** ensure that systems are in place to provide and assure education for all health and social care workers appropriate to their role. This should enable them to develop the knowledge, skills and attitudes necessary to be competent to provide high-quality care for people approaching the end of life and their families and carers.

**Health and social care workers** participate in appropriate training and engage in evaluation and supervision to ensure they have the knowledge, skills and attitudes necessary to be competent to provide high-quality care for people approaching the end of life and their families and carers.

**Commissioners** ensure they commission services that provide and assure education for all health and social care workers appropriate to their role. This should enable them to develop the knowledge, skills and attitudes necessary to be competent to provide high-quality care for people approaching the end of life and their families and carers.

**People approaching the end of life and their families and carers** are cared for and supported by staff with the knowledge, skills and attitudes needed to provide high-quality care.

## **Source guidance**

- [End of life care for adults: service delivery. NICE guideline NG142](#) (2019), recommendations 1.2.2, 1.9.1 and 1.9.2

## **Data source**

### **Structure**

a) Local data collection. The National care of the dying audit – hospitals may be relevant.

b) Local data collection.

c) Local data collection.

### **Outcome**

a) Local data collection. The [NHS Outcomes Framework 2011/12](#) indicators 5a – patient safety incident reporting, 5b – severity of harm, 5c – number of similar incidents, 5.4 – incidence of medication errors causing serious harm (not specific to end of life care).

b) Local data collection.

### **Definitions**

The term ‘workers’ includes paid staff and volunteers.

Training includes formal, accredited training as well as informal or locally provided training. The level of education required for individual workers will depend on their role.

Guidance on workforce training requirements in different settings is available from the source references. Broadly, these recommend the following:

- Curriculum content relating to end of life care contained within pre-registration and undergraduate education for health and social care.
- Training programmes within hospitals, community settings, care homes, ambulance services and other health and social care settings including specialist palliative care services.
- Taking into account communication skills (including issues around loss, grief and bereavement), spiritual care, assessment and care planning, advance care planning, and symptom management as they apply to end of life care.
- Particular account should be taken of the training needs of those workers involved in discussing end of life issues with patients, families and carers.
- Specialist palliative care services to act as an educational resource for training generalist palliative care in the community, including GP practices, district nursing services, care homes and community hospitals, and acute hospitals and other services.

- Medical and district/community nursing out-of-hours workers should be competent in providing general palliative care, including symptom management, the use of syringe drivers, assessment of need, communication skills and providing support both to the patient and to carers in relation to 'do not attempt cardiopulmonary resuscitation' orders (also 'do not attempt resuscitation' orders), and advance decisions.

High-quality care and support is safe, effective and delivers a positive experience for people approaching the end of life and their families and carers.

Strategies for developing the workforce may include the use of the [NHS End of Life Care for All \(e-ELCA\) e-learning resource](#) (commissioned by Department of Health) in conjunction with face to face teaching, work-based learning and peer education.

Training needs within other appropriate settings not specified above, such as homeless hostels and prisons, should also be considered.

Examples of staff competencies in spiritual care are available from [Marie Curie Cancer Care spiritual and religious care competencies for specialist palliative care](#). These outline four different competency levels for staff working in all areas of care, both specialist and non-specialist.

## **Quality statement 16: Workforce planning**

This statement has been removed as it is no longer supported by recommendations. For more details see [update information](#).

## **Using the quality standard**

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

## **Quality measures and national indicators**

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

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

The quality standard makes use of existing measures and indicators provided by the [Department of Health's End of life care strategy: quality markers and measures for end of life care](#) (2009). Users are expected to consider the measures in the context of each quality statement and prioritise those that are most appropriate.

Supplementary NICE quality measures have been developed and are included against each statement where existing suitable measures were not available.

For further information, including guidance on using quality measures, please see [how to use quality standards](#). The standard also highlights where related national quality assured indicators currently exist and measure the quality statement.

## **Diversity, equality and language**

People approaching the end of life should have the opportunity to make informed decisions about their care and treatment, in partnership with health and social care professionals and with their families and carers. Good communication between health and social care professionals and people approaching the end of life and their families and carers is essential and should be sensitive to personal preferences. Treatment and care, and the

information given about it, should be culturally appropriate. It should also be accessible to people with additional needs such as physical, cognitive, sensory or learning disabilities, and to people who do not speak or read English. People approaching the end of life should have access to an interpreter or advocate if needed. Workforces involved in end of life care should adopt an agreed, consistent approach and attitude to end of life care that encourages and accepts patient choice, regardless of their own background, culture and views.

People approaching the end of life and their families and carers should have access to the high-quality care described in this quality standard on the basis of need and that takes into account their preferences, regardless of their individual circumstances, including:

- gender
- ethnicity
- disability
- cognitive impairment
- age
- sexual orientation
- gender reassignment
- religion and belief
- culture or lifestyle
- marriage and civil partnership
- pregnancy and maternity
- socio-economic status
- mental capacity
- diagnosis
- choices they make about their care
- location and setting in which they are receiving care.

## Development sources

### Evidence sources

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

- National End of Life Care Programme. Draft spiritual support and bereavement care quality markers and measures for end of life care (2011)
- NHS National End of Life Programme and National End of Life Care Intelligence Network. End of life care quality assessment tool (2011)
- [Department of Health. End of life care strategy: quality markers and measures for end of life care](#) (2009)
- [Improving supportive and palliative care for adults with cancer. NICE cancer service guidance CSG4](#) (2004)

### Policy context

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

- [Department of Health. End of life care strategy: third annual report](#) (2011)
- [Department of Health. Transparency in outcomes – a framework for quality in adult social care](#) (2011)
- [Department of Health. NHS outcomes framework 2011/12](#) (2010)
- [Department of Health. End of life care strategy: second annual report](#) (2010)
- [Department of Health. End of life care strategy: first annual report](#) (2009)
- [Department of Health. End of life care strategy: quality markers and measures for end of life care](#) (2009)
- [Department of Health. End of life care strategy – promoting high quality care for all adults at the end of life](#) (2008)
- NHS National End of Life Care Programme (2008)



## Definitions and data sources

References included in the definitions and data sources sections can be found below:

- [Audit Commission. National indicator set](#)
- [Care Quality Commission. Essential standards of quality and safety](#) (2010)
- [Care Quality Commission. NHS adult inpatient services survey](#) (2010)
- [Childhood Bereavement Network. Information resources for children](#)
- [Department of Health. Definitions from caring for our future programme](#)
- [Department of Health. End of life care for all \(e-ELCA\)](#)
- [Department of Health. Transparency in outcomes – a framework for quality in adult social care](#) (2011)
- [Department of Health. NHS Operating Framework for 2011/12](#) (2010)
- [Department of Health. Personalisation through person-centred planning](#) (2010)
- [Department of Health. Prioritising need in the context of putting people first: a whole system approach to eligibility for social care – guidance on eligibility criteria for adult social care, England 2010](#) (2010)
- [Department of Health. NHS chaplaincy: meeting the religious and spiritual needs of patients and staff](#) (2003)
- [Dying Matters Coalition. Information resource materials.](#)
- [General Medical Council. Treatment and care towards the end of life: good practice in decision making](#) (2010)
- [General Medical Council. Personal beliefs and medical practice](#) (2008)
- Gold Standards Framework. Prognostic indicator guidance (2008)
- Home Office. Death certification and investigation in England, Wales and Northern Ireland: the report of a fundamental review (2003)
- Information Standards Board. Draft end of life care locality register pilot programme core and comprehensive dataset (2011)
- [Marie Curie Cancer Care. Spiritual and religious care competencies for specialist palliative care](#) (2003)
- [Palliative Care Institute Liverpool. Information resources for children.](#)

- [National Cancer Peer Review Programme. Manual for Cancer Services: psychological support](#) (2011)
- [National Cancer Peer Review Programme. Manual for Cancer Services: rehabilitation](#) (2011)
- [National Council for Palliative Care. Minimum data set \(MDS\) for specialist palliative care services](#)
- [National Council for Palliative Care. Specialist palliative care workforce survey 2009](#) (2009)
- [National End of Life Care Intelligence Network. Predicting death: estimating the proportion of deaths that are 'unexpected'](#) (2011)
- NHS National End of Life Care Programme. End of life care needs assessment pathway
- NHS National End of Life Care Programme. Capacity, care planning and advance care planning in life limiting illness (2011)
- NHS National End of Life Care Programme. End of life locality registers evaluation: final report (2011)
- NHS National End of Life Care Programme Guidance for staff responsible for care after death (last offices) (2011)
- NHS National End of Life Care Programme. Quick guide to identifying patients for supportive and palliative care (2011)
- NHS National End of Life Care Programme. Talking about end of life care: right conversations, right people, right time (2011)
- NHS National End of Life Care Programme. When a patient dies: guidance for professionals on developing bereavement services (2011)
- NHS National End of Life Care Programme. Holistic common assessment of supportive and palliative care needs for adults requiring end of life care (2010)
- NHS National End of Life Care Programme (2010) Supporting people to live and die well: a framework for social care at the end of life.
- National End of Life Care Programme/Department of Health/Skills for Care/Skills for Health (2010) A framework of national occupational standards to support common core competences and principles for health and social care workers working with adults at the end of life

- [NHS Scotland. Supportive and Palliative Care Indicator tool](#)
- [NHS Scotland. Standards for NHS Scotland chaplaincy services](#) (2007)
- [Office for National Statistics. National bereavement survey](#) (2011)
- QOF clinical indicators are available from [www.qof.ic.nhs.uk](http://www.qof.ic.nhs.uk). Full QOF guidance available from [www.nhsemployers.org](http://www.nhsemployers.org)
- [Royal College of General Practitioners. Supporting carers: an action guide for general practitioners and their teams \(second edition\)](#) (2011)
- [Royal College of General Practitioners. Urgent and emergency care clinical audit toolkit](#) (2011)
- Royal College of Physicians. National care of the dying audit – hospitals.
- [Royal College of Physicians. Consultant physicians working for patients: the duties, responsibilities and practice of physicians in medicine fifth edition](#) (2008)
- [Social Care Institute for Excellence](#). Hub where information, resources and links are gathered together to support social care practitioners working with people and their families at the end of life
- [Think Local Act Personal Partnership](#)

## **Related NICE quality standards**

- [Care of dying adults in the last days of life. NICE quality standard 144](#) (2017)
- [Colorectal cancer. NICE quality standard 20](#) (2012)
- [Ovarian cancer. NICE quality standard 18](#) (2012)
- [Lung cancer. NICE quality standard 17](#) (2012)
- [Patient experience in adult NHS services. NICE quality standard 15](#) (2012)
- [Breast cancer. NICE quality standard 12](#) (2011)
- [Chronic obstructive pulmonary disease \(COPD\). NICE quality standard 10](#) (2011)
- [Chronic heart failure. NICE quality standard 9](#) (2011)
- [Chronic kidney disease. NICE quality standard 5](#) (2011)
- [Dementia. NICE quality standard 1](#) (2010)

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## Update information

**August 2021:** This quality standard has been updated due to NICE publishing guidance on [End of life care for adults: service delivery. Quality statements 1, 8 and 9 have been updated. Quality statements 12, 13 and 16 have been withdrawn as they are no longer supported by NICE or NICE-accredited guidance, for example the Department of Health End of life care strategy: quality markers and measures for end of life care has been archived.](#)

**March 2017:** Statement 11 on care in the last days of life has been removed. This is because NICE has published a quality standard for care of dying adults in the last days of life, which covers this topic in detail and replaces this statement.

Some information and links have been updated or removed because resources have moved or are no longer available, for example, the National End of Life Care Programme's End of life care quality assessment tool has been withdrawn.

**October 2013:** Following the [government's independent review of the use of the Liverpool Care Pathway \(LCP\) for the dying patient](#) and the subsequent announcement of the phasing out of the LCP, interim amendments have been made to this quality standard. Direct and indirect references to the LCP have been removed to reflect the gradual phasing out of the LCP and ensure that this quality standard remains current.

## 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.

This quality standard has been included in the [NICE Pathway on end of life care for people with life-limiting conditions](#), 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.

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