NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

End of life care for adults (update)

NICE quality standard

Draft for consultation

11 November 2020 (Consultation)

7 March 2017 (Last updated date)

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| **This quality standard covers** end of life care services, which provide care and support to adults (aged 18 or over) with progressive life-limiting conditions in the final weeks and months of life (or for some conditions, years). It describes high-quality care in priority areas for improvement. It does not cover care during the last few days of life, which is covered by [NICE’s quality standard on care of dying adults in the last days of life](https://www.nice.org.uk/guidance/qs144).  **It is for** commissioners, service providers, health, public health and social care practitioners, and the public.  This quality standard will update the existing [quality standard on end of life care for adults](https://www.nice.org.uk/guidance/QS13) (published November 2011). For more information see [update information](http://www.nice.org.uk/guidance/qsXXX/chapter/Update-information).  This is the draft quality standard for consultation (from 11 November to 9 December 2020). The final quality standard is expected to publish in April 2021. |

# Quality statements

[Statement 1](#_Quality_statement_1:) Adults who are likely to be approaching the end of their life are identified using locally developed systems. **[2011, updated 2021]**

[Statement 2](#_Quality_statement_2:) Adults approaching the end of their life have opportunities to discuss advance care planning. **[new 2021]**

[Statement 3](#_Quality_statement_X) Carers providing end of life care to people at home are supported to access local services that can provide assistance. **[new 2021]**

[Statement 4](#_Quality_statement_[X]) 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]**

[Statement](#_Quality_statement_[X]) 5 Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. **[2011, updated 2021]**

In 2020 this quality standard was updated and statements prioritised in 2011 were updated (2011, updated 2021) or replaced (new 2021). For more information, see [update information](#_Update_information_2).

Statements from the [2011 quality standard for end of life care](https://www.nice.org.uk/guidance/qs13) for adults that are still supported by the evidence may still be useful at a local level.

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| NICE has developed guidance and a quality standard on people’s experiences using adult social care services and adult NHS services (see the [NICE Pathways on people’s experience in social care services](https://pathways.nice.org.uk/pathways/peoples-experience-in-adult-social-care-services) and [patient experience in adult NHS services](https://pathways.nice.org.uk/pathways/patient-experience-in-adult-nhs-services)).  Other quality standards that should be considered when commissioning or providing end of life care services for adults include:   * [Decision making and mental capacity. NICE quality standard 194](https://www.nice.org.uk/guidance/qs194) * [Learning disability: care and support of people growing older. NICE quality standard 187](https://www.nice.org.uk/guidance/qs187) * [Dementia. NICE quality standard 184](https://www.nice.org.uk/guidance/qs184) * [Multimorbidity](https://www.nice.org.uk/guidance/qs153). NICE quality standard 153 * [Care of dying adults in the last days of life. NICE quality standard 144](https://www.nice.org.uk/guidance/qs144) * [Motor neurone disease. NICE quality standard 126](https://www.nice.org.uk/guidance/qs126) * [Supporting adult carers. NICE quality standard in development.](https://www.nice.org.uk/guidance/indevelopment/gid-qs10128)   A full list of NICE quality standards is available from the [quality standards topic library](http://www.nice.org.uk/Standards-and-Indicators/Developing-NICE-quality-standards-/Quality-standards-topic-library). |

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| Questions for consultationQuestions about the quality standard **Question 1** Does this draft quality standard accurately reflect the key areas for quality improvement?  **Question 2** Are local systems and structures in place to collect data for the proposed quality measures? If not, how feasible would it be for these to be put in place?  **Question 3** Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.  **Question 4** Do you think the end of life care service delivery (excluding care in the last days of life) has substantially changed during the COVID-19 pandemic? Can you describe any positive changes that have been introduced as a result of the COVID-19 pandemic? Questions about the individual quality statements **Question 5** For draft quality statement 4: Is there a specific aspect of coordination of care that this quality statement should focus on? If so, please provide details. Local practice case studies **Question 6** Do you have an example from practice of implementing the NICE guideline that underpins this quality standard? If so, please provide details on the comments form. |

# Quality statement 1: Identification

## Quality statement

Adults who are likely to be approaching the end of their life are identified using locally developed systems. **[2011, updated 2021]**

## Rationale

Using a systematic approach enables healthcare professionals to identify adults likely to be approaching the end of their life in a timely and accurate manner. Once identified, people can have their palliative care needs assessed and managed, and their carers and the people important to them can also be offered support. Timely identification gives people the opportunity to make informed decisions about their care, make plans for their future and establish their preferences for where they would like to be cared for and die.

## Quality measures

### Structure

Evidence of local systems to systematically identify adults who are likely to be approaching the end of their life.

**Data source:** Local data collection, for example, local protocols on identification of adults approaching the end of their life.

### Outcome

The proportion of deceased adults who were identified on the palliative care register or had evidence of end of life planning.

Numerator – the number in the denominator who were identified on the palliative care register or had evidence of end of life planning.

Denominator - the number of deceased adults.

**Data source:**Local data collection, for example, local audit of patient records, palliative care registers and end of life registers. [Quality Outcomes Framework](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof) indicator PC001 requires the contractor to establish and maintain a register of all patients in need of palliative care/ support irrespective of age.

## What the quality statement means for different audiences

**Service providers** (such as community care, primary care, secondary care and tertiary care) ensure that systems are in place to identify adults who are likely to be approaching the end of their life. Staff can access and use tools to support this, for example the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool (SPICT).

**Healthcare professionals** (such as GPs, specialists and nurses) are aware of, and use, local systems to identify adults who are likely to be approaching the end of their life. They use their clinical judgement and tools to support this, for example the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool (SPICT).

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services that use a systematic approach to identifying adults who are likely to be approaching the end of their life.

**Adults who are likely to be approaching the end of their life** are identified by the healthcare professionals caring for them. This means that they can have their care and support needs assessed and start to have discussions about the care and treatment they might want in the future.

## Source guidance

[End of life care for adults: service delivery. NICE guideline NG142](https://www.nice.org.uk/guidance/ng142) (2019), recommendation 1.1.1

## Definitions of terms used in this quality statement

### Adults approaching the end of life

Adults in the final weeks and months of life, although for people with some conditions, this could be months or years.

This includes people with:

* advanced, progressive, incurable conditions
* general frailty and coexisting conditions that mean they are at increased risk of dying within the next 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.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

### Identifying adults who are likely to be approaching the end of their life

Adults who are approaching the end of their life can be identified using tools such as the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool (SPICT). There are a number of other ways healthcare professionals may also identify adults as likely to be approaching the end of their life, for example, if they are moving from disease-modifying treatment to palliative care for a life-limiting health condition or through reviews for frailty with coexisting conditions.

[Adapted from [NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), recommendation 1.1.1, and expert opinion]

# Quality statement 2: Advance care planning

## Quality statement

Adults approaching the end of their life have opportunities to discuss advance care planning. **[new 2021]**

## Rationale

Advance care planning gives people the opportunity to have meaningful, patient-led discussions that allow them to make specific decisions and plans for their future care within a structured framework and while they have the capacity to do so. This should happen after a holistic needs assessment to ensure that it fully takes into account all of the things that are important to the person. Advance care planning is an ongoing process, so the person’s advance care plan may change over time, based on the circumstances and their wishes. Early planning for care at the end of life ensures that carers, families and professionals are aware of a person's wishes while they are still fully able to communicate them.

## Quality measures

### Structure

a) Evidence of local arrangements to ensure that adults approaching the end of their life have opportunities to discuss advance care planning.

**Data source:** Local data collection, for example, service specifications or local protocols on advance care planning.

b) Evidence of local arrangements to ensure that advance care planning for adults approaching the end of their life takes into account their holistic needs assessment.

**Data source:** Local data collection, for example, local protocols on advance care planning.

### Process

Proportion of adults approaching the end of their life who have discussions about advance care planning.

Numerator – the number in the denominator who have discussions about advance care planning.

Denominator – the number of adults approaching the end of their life.

**Data source:** Local data collection, for example, local audit of patient records and palliative care register. The [National Audit of Care at the End of Life](https://www.nhsbenchmarking.nhs.uk/nacel) measures the number of people with an advance care plan on arrival at their final admission to hospital.

b) Proportion of adults approaching the end of their life whose advance care plan takes into account their holistic needs assessment.

Numerator – the number in the denominator whose advance care plan takes into account their holistic needs assessment.

Denominator – the number of adults approaching the end of their life who have an advance care plan.

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

### Outcome

Satisfaction of adults approaching the end of their life with the support they receive to plan their future care.

Numerator – the number in the denominator who are satisfied with the support they receive to plan their future care.

Denominator – the number of adults approaching the end of their life.

**Data source:**Local data collection, for example, local patient and carer experience surveys.

## What the quality statement means for different audiences

**Service providers** (such as community care, social care, primary care, secondary care and tertiary care) ensure that systems are in place to give adults approaching the end of their life opportunities to have discussions about advance care planning. The staff carrying this out are trained to have these patient-led discussions and to help the person to develop an advance care plan, taking into account areas important to them identified in the holistic needs assessment. They ensure that systems are in place for advance care planning to be an ongoing process as the person’s condition, circumstances or wishes change.

**Health and social care practitioners** (such as GPs, specialists, nurses and social workers) give adults approaching the end of their life opportunities to discuss advance care planning that take into account their holistic needs assessment. They ensure that advance care planning is an ongoing process, and that advance care plans are reviewed as the person’s condition, circumstances or wishes change.

**Commissioners** (such as clinical commissioning groups, local authorities and NHS England) ensure that that they commission services in which adults approaching the end of their life are offered advance care planning, taking into account the holistic needs assessment, on an ongoing basis as their condition, circumstances or wishes change.

**Adults approaching the end of their life** are given opportunities to talk to health or social care staff about the things that are important to them and use this to help plan for the care and treatment they want in the future.

## Source guidance

[End of life care for adults: service delivery. NICE guideline NG142](https://www.nice.org.uk/guidance/ng142) (2019), recommendation 1.6.1

## Definitions of terms used in this quality statement

### Adults approaching the end of life

Adults in the final weeks and months of life, although for people with some conditions, this could be months or years.

This includes people with:

* advanced, progressive, incurable conditions
* general frailty and coexisting conditions that mean they are at increased risk of dying within the next 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.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

### Advance care planning

Advance care planning is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline.

An advance care planning discussion might include:

* the individual's concerns and wishes
* their important values or personal goals for care
* their understanding about their illness and prognosis
* their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.

Advance care planning is one part of the process of personalised care and support planning.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

### Holistic needs assessment

An assessment that considers all aspects of a person's wellbeing, their spiritual and health and social care needs. Undertaking a holistic needs assessment ensures that the person's concerns and problems are identified so that support can be provided to address them. There are validated tools that can be used to support the assessment process.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

## Equality and diversity considerations

Adults approaching the end of their life should be supported to discuss advance care planning in a meaningful way. They should be provided with information in a format that they can easily understand themselves, or with support, so they can communicate effectively with health and social care practitioners. The information should be in a format that suits their needs and preferences. It should be accessible to people who do not speak or read English, and it should be culturally and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](https://www.england.nhs.uk/ourwork/accessibleinfo/).

# Quality statement 3: Support for carers

## Quality statement

Carers providing end of life care to people at home are supported to access local services that can provide assistance. **[new 2021]**

## Rationale

Practical and emotional support for carers is crucial to help them continue caring for the person approaching the end of their life at home. It is important for their own wellbeing, helping to reduce their levels of stress and illness. It can also help to prepare carers for the death of the person they are caring for.

## Quality measures

### Structure

a) Evidence that local services are in place to support carers providing end of life care to people at home.

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

b) Evidence that carers are helped to access support services.

**Data source:** Local data collection, for example, pathways of carer support.

### Process

Proportion of carers providing end of life care to people at home who are supported to access local services that can provide assistance.

Numerator – the number in the denominator who are supported to access local services that can provide assistance.

Denominator – the number of carers providing end of life care to people at home.

**Data source:** Local data collection, for example, local carer experience surveys and audits of referrals to social prescribing and community support.

### Outcome

a) Proportion of carers providing end of life care to people at home who are satisfied with the support they receive.

Numerator: the number in the denominator who are satisfied with the support they receive.

Denominator: the number of carers providing end of life care to people at home.

**Data source:**Local data collection, for example, [NHS Digital’s Personal social services survey of adult carers](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers) and local carer experience surveys.

b) Carers’ quality of life.

**Data source:**Local data collection, for example, [NHS Digital’s Personal social services survey of adult carers](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers) and local carer experience surveys. A carer-reported quality of life score based on this survey data is included in [NHS Digital’s Measures from the Adult Social Care Outcomes Framework](https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-outcomes-framework-ascof).

## What the quality statement means for different audiences

**Service providers** (community, primary, secondary and tertiary care services, hospices, social care services and voluntary services) ensure that systems and services are in place to provide practical and emotional support for the carers of adults approaching the end of their life. This includes providing palliative care at home, help to use equipment and adaptations, emotional support and any additional help they may need at home.

**Health, social care and voluntary sector practitioners** (such as GPs, specialists, nurses, social workers and voluntary services workers) are aware of local services that can support the carers of adults approaching the end of their life and refer or help carers access services that they may need. The practitioners within these services provide carers with emotional and practical support to care for the adult approaching the end of their life, for example providing palliative care at home and help to use equipment and adaptations.

**Commissioners** (such as clinical commissioning groups, local authorities and NHS England) ensure that they commission services that provide emotional and practical support to the carers of adults approaching the end of their life being cared for at home.

**Carers supporting people at home at the end of their life** can access practical and emotional support locally. This can include support from hospices, palliative home care and practical support to use equipment or adapt the home to help with the person’s care.

## Source guidance

[Supporting adult carers. NICE guideline NG150](https://www.nice.org.uk/guidance/ng150) (2020), recommendation 1.9.12

## Definitions of terms used in this quality statement

### Carers

A carer is someone who helps another person, usually a relative, partner or friend, in their day-to-day life. This term does not refer to someone who provides care professionally or through a voluntary organisation. A young carer is aged under 18. [[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142)]

### Local services that can provide assistance

These are services provided locally, including from local hospices, to support carers when providing end of life care at home and can include:

* replacement care (care that replaces the care normally given by a regular carer)
* palliative home care
* practical support, for example to use equipment and adaptations
* additional help in the home
* emotional support.

[Adapted from [NICE’s guideline on supporting adult carers](https://www.nice.org.uk/guidance/ng150), recommendation 1.9.12 and expert opinion]

## Equality and diversity considerations

In some cases, the carer may be a younger or older person or have a disability or a significant health condition themselves, and this needs to be taken into account when support is being considered and provided.

Carers should be provided with information on support services in a format that they can easily read and understand themselves, or with support, so they can communicate effectively with health, social care and community practitioners. The information should be in a format that suits their needs and preferences. It should accessible to people who do not speak or read English, and be culturally and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](https://www.england.nhs.uk/ourwork/accessibleinfo/).

# Quality statement 4: 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]**

## Rationale

Adults approaching the end of their life are likely to receive care from a range of services and in a number of settings. Coordination of these services is necessary to ensure that there is a shared understanding of the person’s holistic needs and that the person receives end of life care that meets their specific needs and personal preferences.

Information sharing across organisations will help to ensure that adults approaching the end of their life do not have to repeatedly provide information that can be shared between services. Coordination will help to ensure that people are not over-burdened with appointments and home visits. Appointments can be reviewed and optimised if possible, for example, coordinating appointments to avoid multiple visits.

## Quality measures

### Structure

a) Evidence of local processes to coordinate end of life care.

**Data source:** Local data collection, for example, service specifications and joint working agreements between health and social care.

b) Evidence of local arrangements for relevant information about adults approaching the end of their life to be shared with the members of the multipractitioner team involved in their care.

**Data source:** Local data collection, for example, local information-sharing protocols and electronic information-sharing systems.

### Process

a) Proportion of adults approaching the end of their life whose advance care plan is shared with the practitioners involved in their care.

Numerator – the number in the denominator whose advance care plan is shared with the practitioners involved in their care.

Denominator – the number of adults approaching the end of their life who have an advance care plan.

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

b) Proportion of adults approaching the end of their life whose care is coordinated through the multipractitioner team.

Numerator – the number in the denominator whose care is coordinated through the multipractitioner team.

Denominator – the number of adults approaching the end of their life.

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

### Outcome

a) Satisfaction of adults approaching the end of their life with the coordination of their care.

**Data source:**Local data collection, for example, local patient and carer experience surveys.

b) Proportion of adults approaching the end of their life who are cared for in their preferred place.

Numerator: the number in the denominator who are cared for in their preferred place.

Denominator: the number of adults approaching the end of their life.

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

c) Proportion of adults who were identified as approaching the end of their life who died in their preferred place.

Numerator: the number in the denominator who died in their preferred place.

Denominator: the number of adults identified as approaching the end of their life.

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

## What the quality statement means for different audiences

**Service providers** (such as social care, community care, primary care, secondary care and tertiary care) ensure that electronic information-sharing systems are in place so that all practitioners providing care can access up-to-date records and advance care plans. They also ensure that systems are in place making the multipractitioner team responsible for the coordination of care, including coordinating appointments, for people who are approaching the end of their life.

**Health and social care practitioners** (such as GPs, specialists, nurses and social care workers) work with other members of the multipractitioner team to coordinate the care of adults who are approaching the end of their life. They ensure that all relevant information is added to the person’s record and advance care plan so that it can be accessed by other practitioners involved in the person’s care when needed.

**Commissioners** (such as clinical commissioning groups, local authorities and NHS England) ensure that the services they commission have IT systems in place to allow all practitioners providing care to access the records of adults approaching the end of their life. This can be done, for example, by enabling existing IT systems or by introducing a specific system such as the Electronic Palliative Care Coordination System (EPaCCS). They also ensure that the services provide multipractitioner team care and care coordination for adults approaching the end of their life.

**Adults approaching the end of their life** are cared for by a team of health and social care practitioners who work together to coordinate their care and make sure that important information is passed on. This means that the person does not need to keep providing the same information to different people caring for them or attend several appointments on different days that could take place in one visit.

## Source guidance

[End of life care for adults: service delivery. NICE guideline NG142](https://www.nice.org.uk/guidance/ng142) (2019), recommendation 1.8.1

## Definitions of terms used in this quality statement

### Adults approaching the end of life

Adults in the final weeks and months of life, although for people with some conditions, this could be months or years.

This includes people with:

* advanced, progressive, incurable conditions
* general frailty and coexisting conditions that mean they are at increased risk of dying within the next 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.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

### Multipractitioner team

A multipractitioner team is a group of practitioners from different clinical professions, disciplines, organisations and agencies who together make decisions on the recommended treatment for individual patients.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

## Question for consultation

Is there a specific aspect of coordination of care that this quality statement should focus on? If so, please provide details.

# Quality statement 5: Out-of-hours care

## Quality statement

Adults approaching the end of their life have access to support 24 hours a day, 7 days a week. **[2011, updated 2021]**

## Rationale

Adults approaching the end of their life may need support from healthcare services at any time. Being able to access support, including specialist palliative care, as soon as the need arises can help to prevent unnecessary distress to the person approaching the end of their life and their carers by preventing unnecessary visits to accident and emergency departments and hospital admissions. It is also reassuring for carers to know that they can obtain advice at any time of day or night, and this can help to reduce their concerns and anxieties.

## Quality measures

### Structure

a) Evidence of local arrangements to ensure that adults approaching the end of their life have 24-hours-a-day, 7-days-a-week access to a healthcare professional who can access their records and advance care plan.

**Data source:** Local data collection, for example, local service specifications for end of life care and staff rotas.

b) Evidence of local arrangements to ensure an out-of-hours end of life care advice line is in place.

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

c) Evidence of local arrangements to ensure availability of an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life.

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

### Process

a) Proportion of adults approaching the end of their life who have access to a healthcare professional 24 hours a day, 7 days a week.

Numerator – the number in the denominator who have access to a healthcare professional 24 hours a day, 7 days a week.

Denominator – the number of adults approaching the end of their life.

**Data source:** Local data collection, for example, local audits of patient records and patient experience surveys.

b) Proportion of adults approaching the end of their life who have access to an out-of-hours end of life care advice line.

Numerator – the number in the denominator who have access to an out-of-hours end of life care advice line.

Denominator – the number of adults approaching the end of their life.

**Data source:** Local data collection, for example, local audits of patient records and patient experience surveys.

c) Proportion of adults approaching the end of their life who have access to an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life.

Numerator – the number in the denominator who have access to an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life.

Denominator – the number of adults approaching the end of their life.

**Data source:** Local data collection, for example, local audits of patient records and patient experience surveys.

### Outcome

a) Emergency hospital admissions in the 3 months before death.

**Data source:**Local data collection, for example, local audits of patient records and [Public Health England’s Palliative and end of life care data](https://www.gov.uk/government/collections/palliative-and-end-of-life-care).

b) Satisfaction of the person approaching the end of their life, and their carers where appropriate, with the support available.

**Data source:**Local data collection, for example, patient and carer experience surveys and [NHS Digital’s Personal social services survey of adult carers](https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers).

## What the quality statement means for different audiences

**Service providers** (such as community care, primary care, secondary care and tertiary care) ensure that services are in place to support adults approaching the end of their life 24 hours a day, 7 days a week. This includes ensuring that a healthcare professional who can access the person’s records and advance care plan is available. It also includes providing an advice line and an out-of-hours pharmacy service with access to end of life care medications.

**Healthcare professionals** (such as GPs, specialists and nurses) ensure that people approaching the end of their life know about the services that are available to them 24 hours a day, 7 days a week and know how to contact them. They ensure that people approaching the end of their life and their carers know the how these services can support them.

**Commissioners** (such as clinical commissioning groups and NHS England) ensure that they commission services that are available 24 hours a day, 7 days a week for adults approaching the end of their life, including an advice line and access to healthcare professionals and pharmacy services.

**Adults approaching the end of their life and their carers** can access support when they need it. They have access to an advice line, healthcare professionals and to a pharmacy service that has medicines to manage their symptoms at any time of the day or night.

## Source guidance

[End of life care for adults: service delivery NICE guideline NG142](https://www.nice.org.uk/guidance/ng142) (2019), recommendation 1.12.1

## Definitions of terms used in this quality statement

### Adults approaching the end of life

Adults in the final weeks and months of life, although for people with some conditions, this could be months or years.

This includes people with:

* advanced, progressive, incurable conditions
* general frailty and coexisting conditions that mean they are at increased risk of dying within the next 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.

[[NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), terms used in this guideline]

### Out-of-hours support

This includes:

* a healthcare professional available 24 hours a day, 7 days a week, who can access the person's records and advance care plan, and make informed decisions about changes to care
* an out-of-hours end of life care advice line
* an out-of-hours pharmacy service that has access to medicines for symptom management in adults approaching the end of their life.

[Adapted from [NICE’s guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142), recommendation 1.12.1]

## Equality and diversity considerations

Adults approaching the end of their life should be provided with information about the services available to them in a format that they can easily understand themselves, or with support, so they can communicate effectively with health and social care practitioners. The information should be in a format that suits their needs and preferences. The information and the services should be accessible to people who do not speak or read English, and it should be culturally appropriate and age appropriate. People should have access to an interpreter or advocate if needed.

For people with additional needs related to a disability, impairment or sensory loss, information should be provided as set out in [NHS England's Accessible Information Standard](https://www.england.nhs.uk/ourwork/accessibleinfo/).

# Update information

**November 2020:** This quality standard was updated and statements prioritised in 2011 were replaced.

Statements are marked as:

* **[new 2021]** if the statement covers a new area for quality improvement
* **[2011, updated 2021]** if the statement covers an area for quality improvement included in the 2011 quality standard and has been updated.

Statements numbered 1, 8 and 9 in the 2011 version have been updated and are included in the updated quality standard, marked as **[2011, updated 2021]**.

Statements from the 2011 quality standard that are still supported by the evidence may still be useful at a local level, and can be found [here](https://www.nice.org.uk/guidance/qs13).

# 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](https://www.nice.org.uk/standards-and-indicators/timeline-developing-quality-standards) is available from the NICE website.

See our [webpage on quality standard advisory committees](http://www.nice.org.uk/Get-Involved/Meetings-in-public/Quality-Standards-Advisory-Committee) for details of standing committee 2 members who advised on this quality standard. Information about the topic experts invited to join the standing members is available from the [webpage for this quality standard](https://www.nice.org.uk/guidance/indevelopment/gid-qs10140).

This quality standard has been included in the [NICE Pathway on end of life care for people with life-limiting conditions](https://pathways.nice.org.uk/pathways/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](https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-uptake-of-nice-guidance) to help providers make an initial assessment of their service compared with a selection of quality statements. This tool is updated monthly to include new quality standards.

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

## Improving outcomes

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

* quality of life of adults approaching the end of their life
* quality of life of carers of adults approaching the end of their life.

It is also expected to support delivery of the following national frameworks:

* [Adult social care outcomes framework](https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/social-care-collections)
* [NHS outcomes framework](https://digital.nhs.uk/data-and-information/publications/clinical-indicators/nhs-outcomes-framework)
* [Public health outcomes framework for England](https://www.gov.uk/government/collections/public-health-outcomes-framework)
* [Quality framework for public health](https://www.gov.uk/government/publications/quality-in-public-health-a-shared-responsibility).

## Resource impact

NICE quality standards should be achievable by local services. The potential resource impact is considered by the quality standards advisory committee, drawing on resource impact work for the source guidance. Organisations are encouraged to use the [resource impact report for the NICE guideline on end of life care for adults](https://www.nice.org.uk/guidance/ng142/resources) to help estimate local costs.

## Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](https://www.nice.org.uk/guidance/indevelopment/gid-qs10140) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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

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