

End of life care for adults

Quality standard

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This standard is based on NG142 and NG150.

This standard should be read in conjunction with QS5, QS9, QS10, QS12, QS78, QS18, QS17, QS15, QS20, QS50, QS79, QS89, QS91, QS108, QS123, QS126, QS130, QS136, QS144, QS152, QS164, QS168, QS174, QS176, QS177, QS184, QS187 and QS200.

Quality statements

Statement 1 Adults who are likely to be approaching the end of their life are identified using a systematic approach. **[2011, updated 2021]**

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

Statement 3 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 4 Adults approaching the end of their life and their carers have access to support 24 hours a day, 7 days a week. **[2011, updated 2021]**

Statement 5 Carers providing end of life care to people at home are supported to access local services that can provide assistance. **[new 2021]**

In 2021 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](#).

Statements from the 2011 quality standard for end of life care for adults that are still supported by the evidence may still be useful at a local level. The [2011 quality standard on end of life care for adults](#) is available as a pdf.

Quality statement 1: Identification

Quality statement

Adults who are likely to be approaching the end of their life are identified using a systematic approach. [2011, updated 2021]

Rationale

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

Quality measures

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

No routinely collected national data for these measures has been identified, therefore some examples of potential data sources have been suggested.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local protocols on identification of adults approaching the end of their life, including the use of tools such as the Gold Standards Framework Proactive Identification Guidance, the AMBER care bundle

or the Supportive and Palliative Care Indicators Tool.

Outcome

The proportion of adults who have died with progressive life-limiting conditions who were on the palliative care register or had evidence of end of life care planning.

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

Denominator - the number of adults who have died with progressive life-limiting conditions.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records and palliative care registers. Quality Outcomes Framework indicator PC001 requires the contractor to establish and maintain a register of all patients in need of palliative care or support irrespective of age.

What the quality statement means for different audiences

Service providers (such as care homes, community care, mental health care, social care, primary care, secondary care and tertiary care) ensure that systems are in place and staff are trained 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 Proactive Identification Guidance, the AMBER care bundle or the Supportive and Palliative Care Indicators Tool.

Health and social care practitioners (such as care home staff, social workers, mental health clinicians, pharmacists, 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 Proactive Identification Guidance, the AMBER care bundle or the Supportive and Palliative Care Indicators Tool.

Commissioners (such as clinical commissioning groups, local authorities and NHS

England) ensure that they commission services that use a systematic approach to identify adults who are likely to be approaching the end of their life and ensure their staff are trained to do so.

Adults who are likely to be approaching the end of their life are identified by the health and social care practitioners 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 (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, terms used in this guideline]

Systematic approach to 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 Proactive Identification Guidance, the AMBER care bundle or the Supportive and Palliative Care Indicators Tool. There are other ways healthcare professionals may recognise when adults are 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](#), 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, person-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 advance care plan may change over time, based on the person's circumstances and wishes. It is important that the advance care plan is documented and updated during each discussion to ensure the person's current plans are in place. Early planning for care at the end of life helps to ensure that carers, families and professionals are aware of a person's wishes while they are still fully able to communicate them.

Quality measures

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

Some routinely collected national data for these measures has been identified. Where there is no routinely collected national data, some examples of potential data sources have been suggested.

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: Data can be collected from information recorded locally by health and social care practitioners and provider organisations, for example, from 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local protocols on advance care planning.

Process

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

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

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from patient records and palliative care registers. The National Audit of Care at the End of Life 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 documented advance care plan takes into account their holistic needs assessment.

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

Denominator – the number of adults approaching the end of their life who have a

documented advance care plan.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, through face-to-face discussions with adults approaching the end of their life and their carers, from local patient and carer experience surveys, and from bereavement surveys.

What the quality statement means for different audiences

Service providers (such as care homes, hospices, community care, mental health 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 recognise when adults are approaching the end of their life and to have these person-led discussions.

Health and social care practitioners (such as care home staff, social workers, mental health clinicians, GPs, specialists and nurses) give adults approaching the end of their life opportunities to discuss advance care planning that takes 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. They ensure that if the person does not wish to have this discussion at all, this is recorded and their wishes respected.

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. The services they commission ensure that their staff are trained to discuss and record advance care planning, including if the person does not wish to have the discussion at all.

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. As their wishes may change over time, adults approaching the end of their life will be able to have these conversations on a number of occasions, if they want to, to ensure their plans reflect their current wishes. If they do not feel ready to have this discussion, the person can have this discussion at a later date. If they do not wish to have this discussion at all, this is recorded and their wishes respected.

Source guidance

End of life care for adults: service delivery. NICE guideline 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](#), 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](#), 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 goals and wishes, 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](#), terms used in this guideline and expert opinion]

Equality and diversity considerations

A person's culture and religious beliefs may have a significant influence on whether they wish to discuss end of life and advance care planning. Practitioners need to approach these discussions in a sensitive way. If people do not want to speak about their future

needs and care arrangements, this should be respected and clearly recorded.

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, taking into account the person's level of health literacy. 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](#) or the equivalent standards for the devolved nations.

Quality statement 3: 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 planned and emergency 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. Coordination also leads to care being provided more quickly, as it is needed.

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

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

Some routinely collected national data for these measures has been identified. Where there is no routinely collected national data, some examples of potential data sources have been suggested.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example from service specifications and joint working agreements between health and social care. This could include processes to ensure appointments with different specialities are on the same day to avoid the person making repeated visits.

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

and of multipractitioner team and multidisciplinary team meetings.

Outcome

a) 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, through face-to-face discussions with adults approaching the end of their life and their carers, local patient and carer experience surveys and bereavement surveys.

b) Proportion of adults who were identified as approaching the end of their life who had an unplanned admission to hospital.

Numerator: the number in the denominator who had an unplanned admission to hospital.

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, through local audit of hospital admissions data and patient records, local patient and carer experience surveys and bereavement surveys.

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 who have died.

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

local carer experience surveys and bereavement surveys. The [National Audit of Care at the End of Life](#) measures the number of people who have a documented preferred place of death on their final admission.

What the quality statement means for different audiences

Service providers (such as care homes, hospices, ambulance services, mental health care, 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 so that the multipractitioner team can coordinate care, including coordinating appointments, for people who are approaching the end of their life.

Health and social care practitioners (such as care home staff, social workers, mental health clinicians, occupational therapists, pharmacists, paramedics, GPs, specialists and nurses) 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 electronic information-sharing 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 (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, terms used in this guideline]

Carer

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]

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](#), terms used in this guideline]

Quality statement 4: Out-of-hours care

Quality statement

Adults approaching the end of their life and their carers 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 beneficial and supportive 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

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

Some routinely collected national data for these measures has been identified. Where there is no routinely collected national data, some examples of potential data sources have been suggested.

Structure

a) Evidence of local arrangements to ensure that adults approaching the end of their life have access to support 24 hours a day, 7 days a week.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local service specifications for end of life care and staff rotas.

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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records, local patient and carer experience surveys and bereavement 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records, local patient and carer experience surveys and bereavement 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records,

local patient and carer experience surveys and bereavement surveys.

Outcome

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local audits of patient records and [Public Health England's Palliative and end of life care data](#).

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local patient and carer experience surveys, bereavement surveys and [NHS Digital's Personal social services survey of adult carers](#).

What the quality statement means for different audiences

Service providers (such as hospices, community care, primary care, secondary care and tertiary care) ensure that services are in place to support adults approaching the end of their life and their carers 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, and that they have access to equipment out of hours, for example, specialist beds and oxygen. It also includes providing an advice line and an out-of-hours pharmacy service with access to end of life care medications.

Health and social care practitioners (such as social workers, mental health clinicians, pharmacists, GPs, specialists and nurses) ensure that adults approaching the end of their life and their carers 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 adults approaching the end of their life and their carers understand how these services can support them. Practitioners can also access the support services to assist adults approaching the end of their life and their carers.

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 and their carers, 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 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 (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, terms used in this guideline]

Access to 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](#), recommendation 1.12.1]

Equality and diversity considerations

Adults approaching the end of their life and their carers 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, taking into account the person's level of health literacy. 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](#) or the equivalent standards for the devolved nations.

Quality statement 5: 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 and help to ensure they receive bereavement support.

Quality measures

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

Some routinely collected national data for these measures has been identified. Where there is no routinely collected national data, some examples of potential data sources have been suggested.

Structure

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

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from commissioning agreements and local contracts.

b) Evidence that carers can access support services.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from service level agreements and 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from 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: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from local carer experience surveys. The [NHS Digital's Personal social services survey of adult carers](#) collects data on the satisfaction of all carers with the support they receive.

b) Carers' quality of life.

Data source: Data can be collected from information recorded locally by healthcare professionals and provider organisations, for example, from [NHS Digital's 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](#).

What the quality statement means for different audiences

Service providers (community care, mental health care, primary care, secondary care and tertiary care services, hospices, social care 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 end of life care at home, help to use equipment and adaptations, emotional support, respite care and any additional help they may need at home. They can also offer support when the person being cared for is in hospital.

Health, social care and voluntary sector practitioners (such as social workers, mental health clinicians, pharmacists, occupational therapists, GPs, specialists, nurses and voluntary services workers) are aware of local services that can support carers of adults approaching the end of their life and refer or help carers access services that they may need. 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 end of life care at home and help to use equipment and adaptations. They can also offer support when the person being cared for is in hospital.

Commissioners (such as clinical commissioning groups, local authorities and NHS England) ensure that they commission services that provide emotional and practical support to 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, respite care and practical support to use equipment or adapt the home to help with the person's care. They may also be able to access support when the person being cared for is in hospital.

Source guidance

[Supporting adult carers. NICE guideline NG150 \(2020\), recommendation 1.9.12](#)

Definitions of terms used in this quality statement

Carer

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](#)]

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. They 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
- support if the person they care for is admitted to hospital
- emotional support.

[Adapted from [NICE's guideline on supporting adult carers](#), recommendation 1.9.12]

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.

If the adult approaching the end of their life also has a learning disability their carer may also need additional specialist support which should be considered by the practitioner providing care.

The carer's culture and religious beliefs may have a significant influence on whether they

wish to be involved in some of the discussions about end of life care and advance care planning for the person they care for. The practitioners need to approach these discussions in a sensitive way. If carers do not want to speak about the future needs and care arrangements for the person they care for, this should be respected and clearly recorded.

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 be accessible to people who do not speak or read English, and be culturally and age appropriate, taking into account the person's level of health literacy. 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](#) or the equivalent standards for the devolved nations.

Update information

September 2021: 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 from the 2011 quality standard that are still supported by the evidence may still be useful at a local level. The [2011 quality standard on end of life care for adults](#) is available as a pdf.

About this quality standard

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

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

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

See our [webpage on quality standard advisory committees](#) 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](#).

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.

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](#) to help estimate local costs.

Diversity, equality and language

Equality issues were considered during development and [equality assessments for this quality standard](#) are available. Any specific issues identified during development of the quality statements are highlighted in each statement.

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

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Endorsing organisation

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

Supporting organisations

Many organisations share NICE's commitment to quality improvement using evidence-based guidance. The following supporting organisations have recognised the benefit of the quality standard in improving care for patients, carers, service users and members of the public. They have agreed to work with NICE to ensure that those commissioning or providing services are made aware of and encouraged to use the quality standard.

- [Association for Palliative Medicine of Great Britain and Ireland](#)
- [Resuscitation Council \(UK\)](#)
- [British Geriatrics Society](#)
- [National Care Association](#)
- [Royal College of Physicians \(RCP\)](#)
- [Royal College of Nursing \(RCN\)](#)
- [Royal College of Physicians and Surgeons of Glasgow](#)
- [Society for Acute Medicine \(SAM\)](#)