End of life care for adults: service delivery

NICE guideline

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Your responsibility

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals and practitioners are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or the people using their service. It is not mandatory to apply the recommendations, and the guideline does not override the responsibility to make decisions appropriate to the circumstances of the individual, in consultation with them and their families and carers or guardian.

All problems (adverse events) related to a medicine or medical device used for treatment or in a procedure should be reported to the Medicines and Healthcare products Regulatory Agency using the Yellow Card Scheme.

Local commissioners and providers of healthcare have a responsibility to enable the guideline to be applied when individual professionals and people using services wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with complying with those duties.

Commissioners and providers have a responsibility to promote an environmentally sustainable health and care system and should assess and reduce the environmental impact of implementing NICE recommendations wherever possible.

Contents

> This guideline is the basis of QS13.
>
> This guideline should be read in conjunction with NG31, NG61 and CSG4.

Overview

This guideline covers organising and delivering end of life care services, which provide care and support in the final weeks and months of life (or for some conditions, years), and the planning and preparation for this. It aims to ensure that people have access to the care that they want and need in all care settings. It also includes advice on services for carers.

This guideline is intended to be used alongside the NICE guideline on care of dying adults in the last days of life, which covers clinical care for people who are considered to be in the last days of life.

NICE has also produced a guideline on end of life care for infants, children and young people with life-limiting conditions.

Who is it for?

- Commissioners, planners and coordinators of health and social services

- Providers of health and social care

- Health and social care practitioners

- Adults approaching the end of their life, their carers and families

Context

End of life care is defined by NHS England as care that is provided in the 'last year of life'; although for some conditions, end of life care may be provided for months or years. After the Liverpool Care Pathway was withdrawn in 2014, a number of national reports, guidelines and policy documents began to describe the changes needed for a new approach to end of life care services. They identified that high-quality, timely, compassionate personalised care and support planning, including advance care planning, should be accessible to all those who need it. To progress this intention, the models of care and the service delivery arrangements that need to be put in place for people as they approach the end of their life need to be defined.

End of life care may be delivered by disease-specific specialists and their associated teams; by generalists such as primary care teams or hospital-based generalists (for example, elderly care); or by palliative care specialists in hospices, hospitals and community settings. Giving this type of care can ensure that people live well until they die. Care that is given alongside, and to enhance, disease-modifying and potentially life-prolonging therapies, often for years, can be called 'supportive care'. Care that is primarily conservative and aimed at giving comfort and maintaining quality of life in the last months of life is commonly referred to as palliative care. Palliative care particularly aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and continue to offer a support system to help people to live as actively as possible until their death. In this guideline, end of life care includes both supportive and palliative care. However, the terms used for this can vary, for example, end of life care is referred to as 'conservative care' in the NICE guideline on renal replacement therapy and conservative management.

This guideline describes the provision of end of life care services for adults approaching the end of their life with any conditions and diseases. The guideline advises on service models for care in acute settings by disease-specific specialists and their supportive services, and in community settings by primary care or specialists in palliative care (for example, in hospices). It is intended to be used alongside the NICE guideline on care of dying adults in the last days of life, which covers care planning and clinical interventions for people who are considered to be in the last days of life.

Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in NICE's information on making decisions about your care.

Making decisions using NICE guidelines explains how we use words to show the strength (or certainty) of our recommendations, and has information about professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

End of life care includes the care and support given in the final weeks and months of life, and the planning and preparation for this. For 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.

This guideline does not cover the clinical care of adults who are expected to die within a few hours or days. For advice on this, see the NICE guideline on care of dying adults in the last days of life.

1.1 Identifying adults who may be approaching the end of their life, their carers and other people important to them

1.1.1 People managing and delivering services should develop systems to identify adults who are likely to be approaching the end of their life (for example, using tools such as the Gold Standards Framework, the Amber Care Bundle or the Supportive and Palliative Care Indicators Tool [SPICT]). This will enable health and social care practitioners to start discussions about advance care planning, provide the care needed, and to support people's preferences for where they would like to be cared for and die.

1.1.2 Health and social care practitioners should identify carers and other people important to adults who are likely to be approaching the end of their life.

> For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on identifying adults who may be approaching the end of their life, their carers and other people important to them.
>
> Full details of the evidence and the committee's discussion are in the following evidence reviews:
>
> - Evidence review A: identifying people who may be entering the last year of life
>
> - Evidence review C: barriers to accessing end of life care services
>
> - Evidence review H: carer support services
>
> - Evidence review I: information sharing.

1.2 Assessing holistic needs

1.2.1 If it is thought that an adult is approaching the end of their life, carry out

an initial holistic needs assessment with the person and document this. This will enable the right support to be provided when it is needed.

1.2.2   People managing services should ensure that health and social care practitioners caring for adults approaching the end of their life have the training and skills to sensitively carry out holistic needs assessments.

1.2.3   Healthcare practitioners should be aware of the requirement to offer a carer's needs assessment in line with the Care Act 2014 and a young carer's needs assessment in line with the Children and Families Act 2014.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on assessing holistic needs.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review B: timing of referral to palliative care services

- Evidence review C: barriers to accessing end of life care services

- Evidence review H: carer support services.

1.3   Supporting carers

1.3.1   People managing and delivering services should think about what practical and emotional support can be provided to carers of adults approaching the end of their life and review this when needed. For more information, see the NICE guideline on supporting adult carers.

1.3.2   When carers' needs are identified, take into account that the support needs of a young carer are likely to be different to those of an older carer.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on supporting carers.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review H: carer support services

- Evidence review G: involving carers.

1.4 Providing information

1.4.1 For advice on communication, information and shared decision making, see the NICE guidelines on patient experience in adult NHS services, people's experience in adult social care services and shared decision making. Apply the same principles for communication and information giving to carers of all ages.

1.4.2 For people with learning disabilities, use this guideline alongside the recommendations on end of life care in the NICE guideline on care and support of people growing older with learning disabilities.

1.4.3 Support and enable adults approaching the end of their life to actively participate in decision making by having in place:

- processes to establish the amount and type of information they would prefer

- systems to provide information in a way that meets their communication needs and preferences, for example, how it is given (verbally, on paper, by text, email, or other assistive technologies) and provision of professional interpreters

- arrangements to review and anticipate their information needs and preferences as circumstances change.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on providing information.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review G: involving carers.

1.5 Reviewing current treatment

1.5.1 For advice on reducing treatment burden and reviewing medicines and other treatments, see the NICE guidelines on multimorbidity and medicines optimisation.

1.5.2 Develop policies for reviewing treatment within all specialties to meet the changing needs of adults approaching the end of their life and to reduce the burden of unhelpful treatments. Different services should work together and share information about treatment reviews (see section 1.10 on providing end of life care coordination).

1.5.3 The lead healthcare professional should ensure that the person approaching the end of their life is offered opportunities to discuss their existing treatment plans with a healthcare professional. The person's carers and other people important to them should be included in the discussions, if the person agrees. This should include discussing:

- any changes that could optimise care and improve their quality of life (for example, reducing the number of unnecessary routine appointments, organising appointments close to the person's home, starting new treatments or stopping unhelpful treatments)

- community support available to help with their treatment.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on reviewing current treatment.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review D: care coordinator and lead healthcare professional

- Evidence review J: service provision.

1.6 Advance care planning

1.6.1   Service providers should develop policies to ensure that advance care planning is offered to adults who are approaching the end of their life. Policies should take into account under-served and vulnerable groups.

1.6.2   Service providers should develop processes to support carers and other people important to the person to be involved in advance care planning, if the person approaching the end of their life agrees.

1.6.3   Service providers should have systems in place to ensure that adults approaching the end of their life each have a copy of their advance care plan available in their place of residence or with them if admitted to a hospital, care home or hospice.

1.6.4   Service providers should develop processes to take into account the views of carers and other people important to the person if the person approaching the end of their life lacks capacity to make decisions in line with the Mental Capacity Act 2005.

1.6.5   For advice on supporting decision making, assessing mental capacity and advance care planning, see the NICE guideline on decision-making and mental capacity.

1.6.6   For advice on starting advance care planning in adults who:

- are at risk of a medical emergency, see the [NICE guideline on emergency and acute medical care in over 16s](#)

- have motor neurone disease, see the [NICE guideline on motor neurone disease](#)

- have multimorbidity, see the [NICE guideline on multimorbidity](#)

- have dementia, see the [NICE guideline on dementia](#)

- have learning disabilities, see the [NICE guideline on care and support of people growing older with learning disabilities](#).

  A [NICE guideline on social work interventions for adults with complex needs](#) is being developed, with publication expected in January 2022.

1.6.7 For advice on organ donation, see the [NICE guideline on organ donation for transplantation](#).

For a short explanation of why the committee made these recommendations and how they might affect services, see the [rationale and impact section on advance care planning](#).

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- [Evidence review C: barriers to accessing end of life care services](#)

- [Evidence review F: advance care planning](#)

- [Evidence review G: involving carers](#)

- [Evidence review I: information sharing](#).

1.7 Reviewing needs

1.7.1 Develop systems enabling adults approaching the end of their life to have:

- regular discussions with a member of their care team about changes in their health and social care needs and preferences

- repeat assessments of their holistic needs and reviews of their advance care plan when needed, for example at key transition points, such as at discharge from hospital or when the goals of treatment have changed.

For a short explanation of why the committee made this recommendation and how it might affect services, see the rationale and impact section on reviewing needs.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review G: involving carers

- Evidence review J: service provision.

1.8 Communicating and sharing information between services

1.8.1 Adults approaching the end of their life should have care that is coordinated between health and social care practitioners within and across different services and organisations, to ensure good communication and a shared understanding of the person's needs and care.

1.8.2 Use electronic information-sharing systems that are accessible between different services and organisations to enable information to be reviewed, updated and shared efficiently within and between multipractitioner teams, across different services and organisations.

1.8.3 For specific advice on coordinating end of life support in residential settings, see the NICE guideline on people's experience in adult social care services.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on communicating and sharing information between services.

Full details of the evidence and the committee's discussion are in evidence review I: information sharing.

1.9 Providing multipractitioner care

1.9.1 Provide access to the expertise of highly skilled health and social care practitioners, when needed, for adults approaching the end of their life, their carers and other people important to them. They should have the skills to:

- meet complex care and support needs

- anticipate and prevent or minimise crises

- support people's preferences for where they would like to be cared for and die, if possible.

1.9.2 Health and social care practitioners should have the skills to provide care for adults approaching the end of their life who need support in the following areas:

- disease-specific, including symptom management, hydration and nutrition, and access to medication

- physical

- psychological

- social, including support and advice (for example, signposting advice on benefits, finance and third-sector, local or national support services)

- support with activities of daily living, including access to equipment and rehabilitation services

- pastoral, religious and spiritual

- cultural.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on providing multipractitioner care.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review E: multiprofessional team

- Evidence review L: additional services and inappropriate admissions.

1.10 Providing end of life care coordination

1.10.1 Provide end of life care coordination for adults who are approaching the end of their life through:

- community and primary care services for adults, provided by the person's GP or another health or social care practitioner in the primary or community care team

- hospital services for adults whose treatment is based in secondary or tertiary care, provided by health and social care practitioners based in hospices or disease-specific specialists in hospitals.

1.10.2 For people in under-served and vulnerable groups who are approaching the end of their life, provide additional support that takes into account the challenges of coordinating care for people in these groups.

1.10.3 Ensure that there is good communication between health and social care practitioners coordinating community-based care and health and social care practitioners coordinating hospital care.

1.10.4 Health and social care practitioners providing end of life care coordination should:

- offer information to the person approaching the end of their life, their carers and others important to them, about who the multipractitioner team members are (including the lead healthcare professionals in each setting responsible for their care), the roles of the team members and how services are accessed

- ensure that holistic needs assessments are offered, and the person's wishes and needs are discussed and acted on whenever possible

- ensure that care is coordinated across and between the multipractitioner teams and between care settings

- ensure that regular discussions and reviews of care, holistic needs and advance care plans are offered

- share information about the person's care between members of the multipractitioner teams.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on providing end of life care coordination.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review D: care coordinator and lead healthcare professional

- Evidence review G: involving carers.

1.11 Transferring people between care settings

1.11.1 For advice on transitions between care settings for adults with social care needs, see the NICE guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs.

1.11.2 Develop systems to support smooth and rapid transfer between care

settings for adults approaching the end of their life. For example, organise services so that:

- ambulances or other transport services can move people between care settings without delay and in an efficient and compassionate way

- care packages and equipment are available to enable adults approaching the end of their life to move to the place where they would like to be cared for and die.

1.11.3　Develop an agreed transfer policy between ambulance service providers and acute care providers to enable the rapid transfer of adults approaching the end of their life to the place where they would like to be cared for and die whenever rapid transfer is a priority.

For a short explanation of why the committee made these recommendations and how they might affect services, see the rationale and impact section on transferring people between care settings.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review M: optimal transition and facilitating discharge.

1.12 Providing out-of-hours care

1.12.1　Adults approaching the end of their life, their carers and other people important to them should have access to:

- 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.

For a short explanation of why the committee made this recommendation and how it might affect services, see the rationale and impact section on providing out-of-hours care.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review G: involving carers

- Evidence review K: out-of-hours services.

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.

Approaching the end of life

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

It 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.

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.

People managing services

Commissioners, planners and service providers responsible for overseeing local health and social care provision and accountable for public service outcomes.

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.

Lead healthcare professional

A lead healthcare professional is a member of the multipractitioner team who assumes overall clinical responsibility for the delivery of care to a patient. They are usually a senior

doctor or senior nurse.

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.

People important to adults approaching the end of their life

These may include family members and anyone else who the person regards as significant, such as a partner or close friend. It may be someone who the person wants involved in discussions about their care. It is important that health and social care practitioners understand that assumptions should not be made when asking about the people important to the person, for example, assuming everyone is in a heterosexual relationship.

Personalised care and support planning

Personalised care and support planning is a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and wellbeing within the context of their whole life and family situation.

Personalised care and support planning is key for people receiving health and social care services. It is an essential tool to integrate the person's experience of all the services they access so they have one joined-up plan that covers their health and wellbeing needs.

Personalised care and support planning is not to be confused with personalised medicine. The latter is the approach to tailor treatments to people's individual health needs based on their biological risk factors and predictors of response to treatments.

Service providers

All organisations (including primary, secondary, tertiary, ambulance and hospice services) that provide NHS services for people approaching the end of their life.

Shared decision making

Shared decision making is when health and social care professionals and patients work together. This puts people at the centre of decisions about their own treatment and care. During shared decision making, it's important that:

- care or treatment options are fully explored, along with their risks and benefits

- different choices available to the patient are discussed

- a decision is reached together with a health and social care professional.

Recommendations for research

The guideline committee has made the following recommendations for research.

Key recommendations for research

1 Early review of service provision and referral to additional specialist palliative care services

Does early review of service provision and referral to additional specialist palliative care services improve outcomes for adults with progressive non-cancer disease thought to be approaching the end of their life?

Why this is important

There is a body of research into the optimal timing of referral to specialist palliative care in cancer patients, which generally points to earlier referral leading to better patient-reported outcomes. The committee noted that similar evidence is very limited for patients with a non-cancer diagnosis, for example in patients with progressive organ failure, such as advanced heart failure, or patients with life-limiting neurological disease, such as motor neurone disease or dementia. Such patients are typically referred very late to specialist palliative care, if at all. Further research would compare outcomes for people having a combination of early identification and specialist palliative care input with those for people having usual care.

For a short explanation of why the committee made the recommendation for research, see the rationale and impact section on reviewing current treatment.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review D: care coordinator and lead healthcare professional

- Evidence review J: service provision.

2 Electronic registers and information-sharing databases

Which of the electronic information-sharing systems perform best for the care of people approaching the end of their life?

Why this is important

The guideline committee made recommendations on sharing information about people who are approaching the end of their life with other members of the multipractitioner teams involved in their care. The committee was aware that in the past, most information recording and sharing was done using paper-based systems, with information shared between teams and care settings using telephone, fax and emails. However, fully electronic databases and information-sharing systems using internet protocols are becoming more established in the NHS and also in hospice services. NHS Digital has a stated aim to develop joined-up digital systems in the health service. The committee looked for research about which systems performed best and were reliable for sharing confidential information but was unable to find it. The committee were aware of deficiencies in the current systems. Studies conducted in other countries using electronic systems were not applicable to the NHS.

It is therefore recommended that research should be done on the systems that are currently available in the UK. The purpose of this research would be to inform healthcare planners and service providers on the most efficient, reliable, secure, confidential and cost-effective systems to be used for sharing information about people approaching the end of their life across a range of care settings.

For a short explanation of why the committee made the recommendation for research, see the rationale and impact section on communicating and sharing information between services.

Full details of the evidence and the committee's discussion are in evidence review I: information sharing.

3 Frequency of community-based reviews

What are the benefits of planned, regular community-based reviews compared with as-required review of non-cancer patients approaching the end of their life?

Why this is important

There is little relevant research evidence for the optimum frequency of review of people with progressive non-cancer conditions who may be approaching the end of their life. Many of the studies attempted in this area have been conducted in other countries where the healthcare systems are very different from the UK. 'Usual care' for non-cancer conditions tends to provide demand-led review by specialists and primary care staff. This may be appropriate if people are well supported at home or in care settings. However, it could lead to unrecognised deterioration in symptoms or functioning, and place people at risk of crises and unplanned hospital admissions if they are living alone or have little professional support. A policy of regular, planned reviews of patients in their place of residence could improve symptom management, maintain a better level of functioning, prevent crises and may pre-empt emergency hospital visits and admission. However, there is a risk that they could impose unnecessary burdens on the patient, family and the healthcare system.

This research would study non-cancer patients receiving usual care (with or without any concurrent specialist level care), and assess their outcomes against different levels of frequency of planned specialist reviews in the community.

For a short explanation of why the committee made the recommendation for research, see the rationale and impact section on reviewing current treatment.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review D: care coordinator and lead healthcare professional

- Evidence review J: service provision.

4 Discharge and transfer from hospital

What is the optimal way of discharging people approaching the end of their life from hospitals back to their place of residence?

Why this is important

The committee found there was very little evidence on discharging adults approaching the end of their life and transferring them between settings. One of the most important transfers is from hospital to home or the person's place of residence, such as a nursing home, especially when death is imminent. Such discharges are often delayed because of medical or nursing problems, or by unmet social care needs. However, some of these problems could be managed well in the community with key equipment or medication and improved social care. The consequences of delayed discharge can be distressing to the person approaching the end of life and their carers and important people. It could mean people staying and dying in inappropriate care settings, such as an acute hospital ward, when it is not their preferred place to be cared for and die. Delayed discharge would also be unnecessary from a medical or nursing perspective.

Key factors in ensuring prompt discharge with care and compassion include clear communication and processes between services providing care in the 2 settings and also those providing transport.

For a short explanation of why the committee made the recommendation for research, see the rationale and impact section on transferring people between care settings.

Full details of the evidence and the committee's discussion are in the following evidence reviews:

- Evidence review C: barriers to accessing end of life care services

- Evidence review M: optimal transition and facilitating discharge.

Rationale and impact

These sections briefly explain why the committee made the recommendations and how they might affect services. They link to details of the evidence and a full description of the committee's discussion.

Identifying adults who may be approaching the end of their life, their carers and people important to them

Recommendations 1.1.1 and 1.1.2

Why the committee made the recommendations

Talking to people about dying can be difficult and there is often a reluctance to start conversations about preparing for the end of life. Although the evidence was limited, the committee agreed that identifying adults who may be approaching the end of their life supports health and social care practitioners to start discussions about advance care planning. This should ensure that the person near the end of life is provided with the support that they may need now or later to help them stay where they would like to be cared for and die. It also gives them time to consider and re-evaluate their needs with their health and social care practitioners.

The committee wanted to emphasise the importance of identifying people systematically. There are already some systems in use for identifying people approaching the end of their life, which are given as examples in the recommendations. However, there were no studies comparing and evaluating their effectiveness in service delivery so the committee could not recommend a particular system.

The committee noted the importance of identifying people who are at particular risk of missing out on access to end of life care, including people living alone without support, people with learning difficulties and people who are homeless.

The committee agreed that using a shared coordination of care system would improve coordination of care between all health and social care practitioners involved in a person's

care, and in turn improve service delivery.

How the recommendations might affect services

The recommendations reflect current good practice available in some services, but there is variation in how and when people are identified across different patient groups and settings. The recommendations are expected to increase the number of people identified. The net impact on services is uncertain. Some investment will be required to establish systems to systematically identify patients in some areas. However, this will ensure that people approaching the end of their life will receive the appropriate care, and their carers will receive support, which will help to avoid unnecessary hospital admissions.

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Assessing holistic needs

Recommendations 1.2.1 to 1.2.3

Why the committee made the recommendations

The evidence reviewed showed that early assessment was beneficial. However, the studies used different definitions for early and late assessment in various settings and so the evidence wasn't clear enough to recommend an optimal timing for an initial assessment. The committee agreed that an assessment with the person should be carried out to enable the right support to be provided when it is needed.

The evidence showed that carers' quality of life was improved and the burden of care reduced when carers are supported. The committee agreed that assessment of carers' needs is important to ensure they are supported to help care for the person approaching the end of their life. However, these assessments are often overlooked so the recommendation reminds healthcare practitioners that carers should be offered an assessment in line with legislation, and they should refer to social care practitioners accordingly.

How the recommendations might affect services

The recommendations reflect current good practice available in some services, but there

is some variation, for example, in ensuring access to carers' needs assessments.

The assessment of a person's needs will result in appropriate care being delivered. This may reduce some resource use when unnecessary interventions are stopped, but may increase the use of other resources if interventions for end of life care, such as symptom management or aids for daily living, are needed.

The number of carers being assessed may increase, but this should result in better support to help the person stay where they would like to be cared for and die, and may reduce the number of attendances and admissions to hospitals.

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Supporting carers

Recommendations 1.3.1 and 1.3.2

Why the committee made the recommendations

The information and support needs of carers will vary and the evidence did not identify one particular way of supporting carers. However, it did show that carers have better outcomes, such as maintaining quality of life and reduced carer burden, when supported. The committee agreed that health and social care providers should go beyond the strict statutory requirement for carers' assessments to ensure that the needs of carers are considered (including respite and psychological support), and that the varied needs of different carer groups are taken into account.

How the recommendations might affect services

Increased investment may be needed for increased numbers of assessments and increased support accessed. This approach should result in better support for adults approaching the end of their life to stay where they would like to be cared for and die. The impact on hospital admission is uncertain. Increased support may reduce the number of hospital admissions or it may result in increased (and perhaps more appropriate) admissions.

Taking into account the individual support needs of young and older carers should reduce

the physical and emotional strains that are often experienced by carers. This may help reduce the need for, and therefore costs of, interventions for physical and mental health problems common in these groups of carers.

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Providing information

Recommendations 1.4.1 to 1.4.3

Why the committee made the recommendations

The evidence showed that a lack of knowledge about end of life care and the support and services available, and poor communication between adults approaching the end of their life and health and social care practitioners, are barriers to understanding treatment options and confidently making decisions about care.

Based on this evidence and the committee's experience, the recommendations reflect the importance of systematically seeking and acting on the information needs and preferences of people approaching the end of their life, their carers and other people important to them. The committee also acknowledged that people's information needs will vary and change over time, so regular reviews are needed and referral to specialist communication support could be needed.

The committee also noted that service providers across the NHS and adult social care system should follow the NHS England Accessible Information Standard to ensure that the information and communication support needs of disabled people are met.

How the recommendations might affect services

The recommendations reflect good current practice available in some services, but there is variation nationally.

Improving understanding and communication will benefit services, ensuring that people make informed decisions and receive the appropriate care.

Return to recommendations

Reviewing current treatment

Recommendations 1.5.1 to 1.5.3

Why the committee made the recommendations

There was no evidence identified on how and when to carry out an initial review of service provision for people approaching the end of their life. However, the committee agreed that it was important for all lead healthcare professionals responsible for the person's care to review and discuss the person's current care needs with them. In particular, they discussed identifying services that may be needed or could be stopped, and acknowledged that the involvement of too many services can be as problematic as too few.

The committee also agreed that adapting care for treating conditions in adults needing end of life care would help to ensure that the right care is provided at the right time. Policies within different specialties would support this, and the committee were aware that these have been developed for some specialist areas, such as diabetes (see Diabetes UK End of life diabetes care: clinical care recommendations) and for neurological conditions. To encourage more research in this area, the committee developed research recommendations on early review of service provision and referral to additional specialist palliative care services and frequency of community-based reviews.

How the recommendations might affect services

The recommendations reflect current good practice available in some services, but there is variation nationally. Reviewing current treatment of people approaching the end of their life means appropriate care will be given and may reduce the burden of unnecessary appointments and treatments.

Return to recommendations

Advance care planning

Recommendations 1.6.1 to 1.6.7

Why the committee made the recommendations

The evidence for advance care planning was unclear, although it did show some benefit in supporting people to stay where they would like to be cared for and die. The committee acknowledged that the implementation of advance care planning is complex and agreed that there was not enough evidence to recommend a specific service model for advance care planning. However, the committee agreed that advance care planning helps people to achieve the care and support they want, and that policies should be in place to provide it to adults approaching the end of their life. They noted that some under-served and vulnerable groups (for example, people who are homeless and people in prison) may not have opportunities to engage in advance care planning, and that provision for these groups should be highlighted. The committee also felt that advance care planning should not be restricted to planning for possible future loss of mental capacity.

The evidence on barriers to care described how carers felt a lack of control and a lack of trust in health and social care practitioners, resulting in scepticism about the benefits of advance care planning. The committee agreed that better communication and processes to involve carers in advance care planning would help to address this.

Evidence suggested that individual patient-held records did not improve patient satisfaction with communication. However, the committee agreed that a copy of the advance care plan available in the person's home may be useful for health and social care practitioners to refer to in emergency situations when access to other information is unavailable.

How the recommendations might affect services

The recommendations reflect good current practice available in some services, but there is variation in the timing and availability of advance care planning in different areas and for different patient groups.

Advance care planning supports adults approaching the end of their life to be cared for and die in their preferred place, which is often in the community. This may reduce the need for hospital services but increase demand for services in the community. The advance care plan documents the person's current, future and emergency needs, improving coordination of care across the multipractitioner team and should help avoid unnecessary hospital attendances and admissions.

Reviewing needs

Recommendation 1.7.1

Why the committee made the recommendation

There was no evidence to indicate the best time to undertake reviews of service provision for people approaching the end of their life. Every person's journey is individual, reflecting how their health can fluctuate unpredictably, with periods of deterioration, stabilisation and sometimes improvement. In addition, their psychological, social, financial and other support needs will vary, not always in step with the physical illness. The committee therefore agreed that regular reviews of care are important when people are approaching the end of their life to identify when changes in care or other forms of support are needed, for example, when the goals of disease-modifying treatment change.

The committee recognised that regular discussions with the care team would help to identify changes in the person's needs and preferences. They also agreed that repeating holistic needs assessments and reviews of advance care plans would ensure that people continue to receive the right care and support.

How the recommendation might affect services

The recommendation reflects current good practice available in some services, but there is variation nationally. Reviewing the ongoing care of people approaching the end of their life means that appropriate care will be given and may reduce some resource use when unnecessary interventions are stopped.

Communicating and sharing information between services

Recommendations 1.8.1 to 1.8.3

Why the committee made the recommendations

The committee agreed that electronic information systems should be used because they would be the most effective and efficient method to share information. However, the evidence was too limited for the committee to recommend a particular system. The committee developed a research recommendation on electronic registers and information-sharing databases to encourage further research in this area.

The committee did not have the evidence to recommend what information should be shared, but agreed that everyone involved in a person's care should have access to relevant health and social care information, including the person's care plan.

The recommendations are underpinned by the Health and Social Care (Safety and Quality) Act 2015, which introduced a legal duty requiring health and social care bodies to share information when this will facilitate care.

How the recommendations might affect services

The recommendations reflect current good practice available in some services. The use of electronic-based systems to coordinate the care of people approaching the end of their life has been increasing across England and Wales. The committee agreed that there is variation in the implementation of these systems across the NHS and investment would be needed in areas without systems in place. The committee considered that electronic systems would result in more efficient, well-coordinated care through better access to information, reducing duplication and improving communication.

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Providing multipractitioner care

Recommendations 1.9.1 and 1.9.2

Why the committee made the recommendations

The evidence showed that a multipractitioner approach to care was favourable and had a positive impact on supporting adults to stay where they would like to be cared for and die. The committee agreed that the skills and expertise of many specialties and disciplines is needed to meet people's varied and changing needs. However, there is no clear evidence

on the ideal composition of a multipractitioner team and so instead of identifying specific roles, the committee set out the type of support people may need access to as they approach the end of their life.

How the recommendations might affect services

The recommendations reflect current good practice available in some services, but there is variation nationally. Care that meets the person's identified needs and is delivered by health and social care practitioners with the relevant skills may reduce costs by minimising crises and helping to avoid emergency unplanned care and unnecessary hospital attendances and admissions. However, this will require some investment upstream.

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Providing end of life care coordination

Recommendations 1.10.1 to 1.10.4

Why the committee made the recommendations

The evidence on identifying barriers to accessing services showed that continuity and coordination of care are often identified as being unsatisfactory for adults approaching the end of their life and their carers. The evidence also highlighted a lack of information and poor communication with carers, which could be improved with better coordination of care.

The committee agreed that good coordination of care and effective communication systems are especially important when people have contact with multiple services and organisations and for under-served and vulnerable groups.

The committee also agreed that good coordination of care should include systems to review appointments and home visits, both to support efficiency of care and also to avoid overwhelming the person with multiple visits from different services.

The evidence showed that having someone to organise care was of some benefit, particularly in reducing unscheduled and emergency hospital visits and admissions. However, it was not clear if this should be a specific role or who should do this. Therefore,

the committee listed the key principles within end of life care coordination that community, hospital and hospice services could provide in collaboration rather than specifying who should take on this role and where it should be located.

How the recommendations might affect services

The recommendation reflects current good practice available in some services, but there is variation nationally. In areas where good coordination of care is lacking, it should result in more efficient service provision and help to minimise crises, and support people to stay where they would like to be cared for and die. Good care coordination should also reduce the use of unnecessary services and avoid duplication of care.

Care coordination by health and social care professionals is taking place currently in the NHS but the committee was uncertain how extensively it is practised. Additional resources may be needed to coordinate care across services and deliver the key roles of end of life care coordination, but it should help to reduce the use of unnecessary services and avoid duplication of care.

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Transferring people between care settings

Recommendations 1.11.1 to 1.11.3

Why the committee made the recommendations

There was very little evidence on transferring adults between settings when they are approaching the end of their life. However, the committee agreed that the availability of efficient and timely transfer is important to ensure that people can be moved quickly, when needed, to where they would like to be cared for and die.

The committee also discussed the consequences of delayed transfer, which can result in people staying in inappropriate care settings or being cared for and dying in settings other than where they would like to be cared for and die. They also discussed how clear communication and processes between services providing care and those providing transport can help to avoid delays and enable efficient transfer.

The committee developed recommendations to reinforce good practice and support the advice in NICE's guideline on transition between inpatient hospital settings and community or care home settings for adults with social care needs. The committee also noted that more research is needed to determine the optimal service configuration for transfer of people with different conditions and at different stages as people approach the end of their life (see the research recommendation on discharge and transfer from hospital).

The committee also agreed that poor and slow access to care packages and equipment can delay transfer between settings and prevent people from being cared for and dying in their preferred place, so highlighted the need to organise this support to enable timely transfer.

How the recommendations might affect services

Effective and timely transfer is likely to reduce the number of people dying in hospital, because most people wish to die in a community setting (for example, their own home or care home, or in a hospice). This may reduce the need for hospital services but increase demand for services in the community.

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Providing out-of-hours care

Recommendation 1.12.1

Why the committee made the recommendation

The evidence for providing an out-of-hours service showed some benefit in supporting people to stay where they would like to be cared for and die. The committee agreed that the services described in the studies reflected existing out-of-hours services in areas of good practice. However, there was evidence that elements of service provision important for people approaching the end of their life may be variable or lacking, so these were the focus for the recommendation.

The evidence supported the committee's experience that access to healthcare advice is critical in providing reassurance and ensuring people have access to the services they need. The committee agreed that a healthcare practitioner should be available at all times

to provide this, and that they would need access to the person's records and advance care plan, preferably through a shared electronic information system, to enable them to make informed decisions about care.

Evidence exploring the views of people approaching the end of their life and their carers highlighted the importance of having access to advice from someone who has expertise and understands their needs. The committee agreed that an out-of-hours end of life care advice line could help to provide this support.

Another common concern for people at the end of life and their carers is the limited provision of pharmacy services outside traditional working hours. The committee discussed how a lack of access to medicines that may be needed quickly can result in people being transferred and admitted to hospital.

An analysis of the evidence for providing a dedicated out-of-hours end of life care advice line and an out-of-hours pharmacy service showed that the costs of providing these services could be balanced by the savings incurred by a relatively small reduction in emergency admissions and length of stay of admissions, and an increase in the number of people remaining in the community. The committee noted that the net resource impact of caring for people in the community is uncertain. On balance, they felt that providing out-of-hours care was a good use of resources and key to meeting the needs of patients.

How the recommendation might affect services

Current provision of out-of-hours services is variable nationally, but the recommendation reflects current good practice in some areas. The committee are uncertain how extensively it is practised. Where services such as an out-of-hours pharmacy service or dedicated end of life care advice line are lacking, increased resources may be needed to set up these services. However, this is likely to reduce the number of people being transferred to hospital for care that could be given at home. This may reduce the need for hospital services but increase demand for services in the community.

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Finding more information and resources

You can see everything NICE says on end of life care for adults in NICE's interactive flowchart on end of life care for people with life-limiting conditions.

To find out what NICE has said on topics related to this guideline, see our web page on end of life care.

For full details of the evidence and the guideline committee's discussions, see the evidence reviews. You can also find information about how the guideline was developed, including details of the committee.

NICE has produced tools and resources to help you put this guideline into practice. For general help and advice on putting NICE guidelines into practice, see resources to help you put guidance into practice.

Update information

October 2021: We added a link to NICE's shared decision making guideline in recommendation 1.4.1.

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