

1 **NATIONAL INSTITUTE FOR HEALTH AND CARE**
2 **EXCELLENCE**

3 **Guideline**

4 **End of life care for adults: service delivery**

5 **Draft for consultation, April 2019**

This guideline covers organising and delivering end of life care services for adults approaching the end of their life. It aims to ensure that people have access to end of life services in all care settings, according to their needs and wishes. It also includes advice on services for carers and other people important to adults who are approaching the end of their life.

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.

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 people important to them

This draft of the guideline contains:

- the draft recommendations
- recommendations for research
- rationale and impact sections that explain why the committee made the recommendations and how they might affect services
- the guideline context.

Information about how the guideline was developed is on the [guideline's page](#) on the NICE website. This includes the evidence reviews, the scope, and details of the

committee and any declarations of interest.

Full details of the evidence and the committee's discussion on the recommendations are in the [evidence reviews](#).

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1 Recommendations

People have the right to be involved in discussions and make informed decisions about their care, as described in [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 prescribing medicines (including off-label use), professional guidelines, standards and laws (including on consent and mental capacity), and safeguarding.

2 **1.1 Identifying adults who may be approaching the end of their** 3 **life, their carers and other people important to them**

4 1.1.1 [People managing services](#) should develop systems to identify adults who
5 are likely to be [approaching the end of their life](#). This will enable health
6 and social care practitioners to start discussions about advance care
7 planning and provide the support needed to help people stay in their
8 preferred place of care.

9 1.1.2 Health and social care practitioners should identify [carers](#) and other
10 [people important to adults](#) who are likely to be approaching the end of
11 their life.

To find out why the committee made the recommendations on identifying adults approaching the end of their life, their carers and other people important to them and how they might affect services, see [rationale and impact](#).

12 **1.2 Assessing holistic needs**

13 1.2.1 If it is thought an adult is approaching the end of their life, carry out an
14 initial [holistic needs assessment](#) to enable the right support to be provided
15 when it is needed.

1 1.2.2 Health and social care practitioners caring for adults approaching the end
2 of their life should have the skills to sensitively carry out holistic needs
3 assessments.

4 1.2.3 Be aware of the local systems to offer a carer's needs assessment in line
5 with the [Care Act 2014](#) and a young carer's needs assessment in line with
6 the [Children and Families Act 2014](#).

To find out why the committee made the recommendations on assessing holistic needs and how they might affect services, see [rationale and impact](#).

7 **1.3 Providing information**

8 1.3.1 For advice on communication, information and shared decision making,
9 see the NICE guidelines on [patient experience in adult NHS services](#) and
10 [people's experience in adult social care services](#). Apply the same
11 principles for communication and information giving to carers of all ages.

12 1.3.2 Support adults approaching the end of their life to actively participate in
13 decision making by having in place:

- 14 • processes to establish the amount and type of information they would
15 prefer
- 16 • systems to provide information in a way that meets their communication
17 needs and preferences, for example, how it is given (verbally, on paper,
18 by text, email, or other assistive technologies) and provision of
19 professional interpreters
- 20 • arrangements to review and anticipate their information needs and
21 preferences as circumstances change.

To find out why the committee made the recommendations on providing information and how they might affect services, see [rationale and impact](#).

22

1 **1.4** ***Supporting carers***

2 1.4.1 When carers' needs are assessed, take into account that the support
3 needs of a young carer are likely to be different to those of an older carer.

To find out why the committee made the recommendation on supporting carers and how it might affect services, see [rationale and impact](#).

4 **1.5** ***Reviewing current treatment***

5 1.5.1 For advice on reducing treatment burden and reviewing medicines and
6 other treatments see the NICE guidelines on [multimorbidity](#) and [medicines](#)
7 [optimisation](#).

8 1.5.2 Develop policies for reviewing treatment across specialities to meet the
9 changing needs of adults approaching the end of their life and to reduce
10 the burden of unhelpful treatments.

11 1.5.3 The [lead healthcare professional](#) for the person's care in each care setting
12 should discuss all existing treatment plans with the person approaching
13 the end of their life and, with the person's consent, their carers and other
14 people important to them. This should include discussing:

- 15
- 16 • any changes that could optimise care and improve their quality of life
17 (for example, reducing the number of unnecessary routine
18 appointments, organising appointments close to the person's home,
19 starting new treatments or stopping unhelpful treatments)
 - community support available to help with their treatment.

To find out why the committee made the recommendations on reviewing current treatment and how they might affect services, see [rationale and impact](#).

20 **1.6** ***Advance care planning***

21 1.6.1 [Service providers](#) should develop policies to ensure that [advance care](#)
22 [planning](#) with adults who are approaching the end of their life is carried
23 out.

- 1 1.6.2 Service providers should develop processes to:
- 2 • support carers and other people important to the person to be involved
- 3 in advance care planning, if the person approaching the end of their life
- 4 consents
- 5 • take into account the views of carers and other people important to the
- 6 person if the person approaching the end of their life lacks capacity to
- 7 make decisions in line with the [Mental Capacity Act 2005](#).
- 8 1.6.3 For advice on supporting decision making, assessing mental capacity and
- 9 advance care planning, see the NICE guideline on [decision-making and](#)
- 10 [mental capacity](#).
- 11 1.6.4 For advice on starting advance care planning in adults who are at risk of a
- 12 medical emergency, see the NICE guideline on [emergency and acute](#)
- 13 [medical care in over 16s: service delivery and organisation](#).

To find out why the committee made the recommendations on advance care planning and how they might affect services, see [rationale and impact](#).

14 **1.7 Reviewing needs**

- 15 1.7.1 Develop systems enabling adults approaching the end of their life, to
- 16 have:
- 17 • regular discussions with a member of their care team about changes in
- 18 their health and social care needs and preferences
- 19 • repeat assessments of their holistic needs and reviews of their advance
- 20 care plan when needed, for example at key transition points, such as at
- 21 discharge from hospital or when the goals of treatment have changed.

To find out why the committee made the recommendation on reviewing needs and how it might affect services, see [rationale and impact](#).

1 **1.8** ***Communicating and sharing information between services***

2 1.8.1 Adults approaching the end of their life should have care that is
3 coordinated between health and social practitioners within and across
4 different services and organisations, to ensure good communication and a
5 shared understanding of the person's needs and care.

6 1.8.2 Use standardised electronic information-sharing systems that are
7 accessible between different services and organisations, to enable
8 information to be reviewed, updated and shared efficiently within and
9 between multipractitioner teams, across different services and
10 organisations.

11 1.8.3 Have systems in place to ensure that adults approaching the end of their
12 life have a printed copy of their advance care plan available in their usual
13 place of residence or with them if admitted to a hospital or hospice.

14 1.8.4 For specific advice on coordinating end of life support in residential
15 settings, see the NICE guideline on [people's experience in adult social](#)
16 [care services](#).

To find out why the committee made the recommendations on communicating and sharing information between services and how they might affect services, see [rationale and impact](#).

17 **1.9** ***Providing multipractitioner care***

18 1.9.1 Provide adults approaching the end of their life, their carers and other
19 people important to them with access to the expertise of highly skilled
20 health and social care practitioners, when needed, to:

- 21
- 22 • meet complex care and support needs
 - 23 • prevent and minimise crises
 - 24 • support people to stay in their preferred place of care, if possible.

25 1.9.2 Provide care from health and social care practitioners with the skills to meet the person's identified needs, which may be:

- 1 • disease-specific, including symptom management and access to
- 2 medication
- 3 • physical
- 4 • psychological
- 5 • social, including support and advice (for example, signposting advice
- 6 on benefits and finance)
- 7 • support with activities of daily living, including access to equipment and
- 8 rehabilitation services
- 9 • spiritual
- 10 • cultural.

To find out why the committee made the recommendations on providing multipractitioner care and how they might affect services, see [rationale and impact](#).

11 **1.10 Providing end of life care coordination**

12 1.10.1 Provide end of life care coordination for adults who are approaching the

13 end of their life through:

- 14 • community and primary care services for adults being cared for in their
- 15 usual place of residence, for example, provided by the person's GP or
- 16 another health and social care practitioner in the primary or community
- 17 care team
- 18 • hospital services for adults whose treatment is based in secondary or
- 19 tertiary care.

20 1.10.2 End of life care coordination based in secondary or tertiary care (for

21 example, provided by health and social care practitioners based in

22 hospices or disease-specific specialists in hospitals) should ensure there

23 is communication with the health and social care practitioners providing

24 community-based care.

25 1.10.3 Health and social care practitioners providing end of life care coordination

26 should:

- 1 • provide information to the person approaching the end of their life, their
2 carers and others important to them, about who the multipractitioner
3 team members are (this should include the lead healthcare
4 professionals in each setting responsible for their care), the roles of the
5 team members and how services are accessed
- 6 • ensure that holistic needs assessments are done and the person's
7 needs are discussed and acted on
- 8 • ensure that care is coordinated across and between the
9 multipractitioner teams and between care settings
- 10 • ensure that regular discussions and reviews of care and advance care
11 plans take place
- 12 • share information about the person's care between members of the
13 multipractitioner teams.

To find out why the committee made the recommendations on providing end of life care coordination and how they might affect services, see [rationale and impact](#).

14 **1.11 *Transferring people between care settings***

15 1.11.1 For advice on transitions between care settings for adults with social care
16 needs see the NICE guideline on [transition between inpatient hospital
17 settings and community or care home settings for adults with social care
18 needs](#).

19 1.11.2 Develop systems to support the smooth and rapid transfer between care
20 settings for adults approaching the end of their life. For example, organise
21 services so that:

- 22 • ambulances or other transport services can move people between care
23 settings without delay and in an efficient and compassionate way
- 24 • care packages and equipment are available to enable adults
25 approaching the end of their life to move to their preferred place of
26 care.

- 1 1.11.3 Develop an agreed transfer policy between ambulance service providers
2 and acute care providers to enable the rapid transfer of adults
3 approaching the end of their life to their preferred place of care whenever
4 rapid transfer is a priority.

To find out why the committee made the recommendations on transferring people between care settings and how they might affect services, see [rationale and impact](#).

5 **1.12 Providing out-of-hours care**

- 6 1.12.1 Adults approaching the end of their life, their carers and other people
7 important to them should have access to:

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

To find out why the committee made the recommendation on providing out-of-hours care and how it might affect services, see [rationale and impact](#).

14 **Terms used in this guideline**

15 **Advance care planning**

16 A discussion about personalised care and support planning between a person and
17 their health and social care providers. This includes current, future and emergency
18 care planning as well as covering the possibility of future loss of mental capacity. If
19 the person wishes, their family and friends may be included in advance care
20 planning.

21 An advance care planning discussion might include the person's:

- 22 • concerns, wishes and preferences for place of care

- 1 • important values or personal goals for care
- 2 • understanding about their illness and prognosis
- 3 • preferences and wishes for types of care or treatment (including declining these)
- 4 in the future and discussion of the care available
- 5 • preferences, wishes and religious or cultural requirements for care after death
- 6 and funeral arrangements.

7 **Approaching the end of life**

8 People are 'approaching the end of life' when they are likely to die within the next
9 12 months. This includes people with:

- 10 • advanced, progressive, incurable conditions
- 11 • general frailty and coexisting conditions that mean they are at increased risk of
- 12 dying within the next 12 months.
- 13 • existing conditions if they are at risk of dying from a sudden acute crisis in their
- 14 condition
- 15 • life-threatening acute conditions caused by sudden catastrophic events.

16 This guideline does not cover adults whose death is imminent (expected within a few
17 hours or days). For advice on the clinical care of adults in the last days of life, see
18 the NICE guideline on [care of dying adults in the last days of life](#).

19 **Carers**

20 A carer is someone who helps another person, usually a relative, partner or friend, in
21 their day-to-day life. This term does not refer to someone who provides care
22 professionally or through a voluntary organisation. A young carer is someone aged
23 18 or under.

24 **People managing services**

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

27 **Holistic needs assessment**

28 An assessment that considers all aspects of a person's wellbeing and health and
29 social care needs. Undertaking a holistic needs assessment ensures that the

1 person's concerns and problems are identified so that support can be provided to
2 address them.

3 **Lead healthcare professional**

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

7 **Multipractitioner team**

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

11 **People important to adults**

12 These may include family members and anyone else who the person regards as
13 significant, such as a partner or close friend. It may be someone who the person
14 wants involved in discussions about their care.

15 **Service providers**

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

18 **Recommendations for research**

19 The guideline committee has made the following high-priority recommendations for
20 research. For details of all the committee's recommendations for research, see the
21 [evidence reviews](#).

22 ***1 Early review of service provision and referral to additional*** 23 ***specialist palliative care services***

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

1 **Why this is important**

2 There is a body of research into the optimal timing of referral to specialist palliative
3 care in cancer patients, which generally points to earlier referral leading to better
4 patient-reported outcomes. The committee noted that similar evidence does not exist
5 for patients with a non-cancer diagnosis, for example in patients with progressive
6 organ failure, such as advanced heart failure, or dementia. Such patients are
7 typically referred very late to specialist palliative care, if at all. Further research would
8 compare outcomes for people having a combination of early identification and
9 specialist palliative care input with those for people having usual care.

10 ***2 Electronic registers and information-sharing databases***

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

13 **Why this is important**

14 The guideline committee made recommendations on sharing information about
15 people who are approaching the end of their life with other members of the
16 multipractitioner teams involved in their care. The committee was aware that in the
17 past, most information recording and sharing was done using paper-based systems,
18 with information shared between teams and care settings using telephone, fax and
19 emails. However, fully electronic databases and information-sharing systems using
20 internet protocols are becoming more established in the NHS and also in hospice
21 services. The committee looked for research about which systems performed best
22 and were reliable for sharing confidential information, but was unable to find it.
23 Studies conducted in other countries using electronic systems were not applicable to
24 the NHS.

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

1 **3 Frequency of community-based reviews**

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

4 **Why this is important**

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

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

21 **4 Discharge and transfer from hospital**

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

24 **Why this is important**

25 The committee found there was very little evidence on discharging adults
26 approaching the end of their life and transferring them between settings. One of the
27 most important transfers is from hospital to home or the person's usual place of
28 residence, such as a nursing home, especially when death is imminent. Such
29 discharges are often delayed because of medical or nursing problems, or by unmet
30 social care needs. However, some of these problems could be managed well in the

1 community with key equipment or medication and improved social care. The
2 consequences of delayed discharge include people staying and dying in
3 inappropriate care settings, such as an acute hospital ward, when it is not their
4 preferred place of care and unnecessary from a medical or nursing perspective.

5 Key factors in ensuring prompt discharge with care and compassion include
6 importance of having clear communication and processes between services
7 providing care in the two settings, and also those providing transport.

8 **Rationale and impact**

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

11 [Recommendations 1.1.1 to 1.1.2](#)

12 **Why the committee made the recommendations**

13 Although the evidence was limited, the committee agreed that identifying adults who
14 may be approaching the end of their life supports health and social care practitioners
15 to start discussions about advance care planning. This should provide the person
16 near the end of life the support that they may need now or later to help them stay in
17 their preferred place of care. It also gives them time to consider and re-evaluate their
18 needs with their health and social care practitioners.

19 The committee wanted to emphasise the importance of identifying people
20 systematically. There are already some systems in use for identifying people
21 approaching the end of their life (for example, the Gold Standards Framework,
22 Amber Care Bundle, Supportive and Palliative Care Indicators Tool (SPICT)).
23 However, there were no studies comparing and evaluating their effectiveness in
24 service delivery so the committee could not recommend a particular system.

25 The committee agreed that the use of a shared coordination of care system would
26 improve coordination of care between all health and social care practitioners
27 involved in a person's care and in turn improve service delivery.

1 **How the recommendations might affect services**

2 The recommendations reflect current good practice available in some services, but
3 there is variation in how and when people are identified across different patient
4 groups and settings. The recommendations are expected to increase the number of
5 people identified. However, this is not likely to have a significant resource impact
6 because early identification will ensure that people approaching the end of their life
7 will receive the appropriate care, and their carers will receive support, which will help
8 to avoid unnecessary hospital admissions.

9 Full details of the evidence and the committee's discussion are in the following
10 [evidence reviews](#):

- 11 • A: identifying adults approaching the end of their life, their carers and people
12 important to them
- 13 • C: barriers to accessing end of life care services
- 14 • H: carer support services and
- 15 • I: information sharing.

16 [Return to recommendations](#)

17 ***Assessing holistic needs***

18 [Recommendations 1.2.1 to 1.2.3](#)

19 **Why the committee made the recommendations**

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

25 The evidence showed that carers' quality of life was improved and the burden of care
26 reduced when carers are supported. The committee agreed that assessment of
27 carers' needs is important to ensure they are supported to help care for the person
28 approaching the end of their life. However, these assessments are often overlooked

1 so the recommendation reminds health and social care practitioners that carers
2 should be offered an assessment in line with legislation.

3 **How the recommendations might affect services**

4 The recommendations reflect current good practice available in some services, but
5 there is some variation, for example in ensuring access to carers' needs
6 assessments.

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

11 The number of carers being assessed may increase, but this should result in better
12 support to help the person stay in their preferred place of care, and may reduce the
13 number of attendances and admissions to hospitals.

14 Full details of the evidence and the committee's discussion are in the following
15 [evidence reviews](#):

- 16 • B: timing of referral to palliative care services
- 17 • C: barriers to accessing end of life care services
- 18 • H: carer support services.

19 [Return to recommendations](#)

20 ***Providing information***

21 [Recommendations 1.3.1 and 1.3.2](#)

22 **Why the committee made the recommendations**

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

27 Based on this evidence and the committee's experience, the recommendations
28 reflect the importance of systematically seeking and acting on the information needs

1 and preferences of people approaching the end of their life, their carers and other
2 people important to them. The committee also acknowledged that peoples'
3 information needs will vary and change over time, so regular reviews are needed.

4 **How the recommendations might affect services**

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

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

9 Full details of the evidence and the committee's discussion are in the following
10 [evidence reviews](#):

- 11 • C: barriers to accessing end of life care services
- 12 • G: involving carers.

13 [Return to recommendations](#)

14 ***Supporting carers***

15 [Recommendation 1.4.1](#)

16 **Why the committee made the recommendation**

17 The information and support needs of carers will vary and the evidence did not
18 identify one particular way of supporting carers. However, it did show that carers
19 have better outcomes, such as maintaining quality of life and reduced carer burden,
20 when supported. The committee agreed that health and social care practitioners
21 should go beyond the strict statutory requirement for carers' assessments to ensure
22 that they consider the needs of carers and to take into account how needs will vary
23 for different carer groups.

24 **How the recommendation might affect services**

25 Increased investment may be needed for increased numbers of assessments and
26 increased support accessed. This approach should result in better support for adults
27 approaching the end of their life to stay in their preferred place of care longer, and
28 may reduce the number of hospital admissions.

1 Taking into account the individual support needs of young and older carers should
2 reduce the physical and emotional strains that are often experienced by carers. This
3 may help reduce the need for, and therefore costs of, interventions for physical and
4 health mental problems common in these groups of carers.

5 Full details of the evidence and the committee's discussion are in the following
6 [evidence reviews](#):

- 7 • C: barriers to accessing end of life care services
- 8 • H: carer support services
- 9 • G: involving carers.

10 [Return to recommendations](#)

11 ***Reviewing current treatment***

12 [Recommendations 1.5.1 to 1.5.3](#)

13 **Why the committee made the recommendations**

14 There was no evidence identified on how and when to carry out an initial review of
15 service provision for people approaching the end of their life. However, the
16 committee agreed that it was important for all lead healthcare professionals
17 responsible for the person's care to review and discuss the person's current care
18 needs with them. In particular, they discussed identifying services that may be
19 needed or could be stopped, and acknowledged that the involvement of too many
20 services can be as problematic as too few. The committee also agreed that adapting
21 care for treating conditions in adults needing end of life care would help ensure that
22 the right care is provided at the right time.

23 To encourage more research in this area, research recommendations were also
24 developed (see [research recommendations 1 and 3](#)).

25 **How the recommendations might affect services**

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

1 Full details of the evidence and the committee's discussion are in the following
2 [evidence reviews](#):

- 3 • D: care coordinator and lead health professional
- 4 • J: identifying the need for additional services; timing and frequency of review of
5 services.

6 [Return to recommendations](#)

7 ***Advance care planning***

8 [Recommendations 1.6.1 to 1.6.4](#)

9 **Why the committee made the recommendations**

10 The evidence for advance care planning was unclear, although it did show some
11 benefit in supporting people to stay in their preferred place of care. There was not
12 enough evidence for the committee to recommend a specific service model for
13 advance care planning. However, the committee agreed that advance care planning
14 helps people to achieve the personalised care and support they want, and that
15 processes should be in place to provide it to adults approaching the end of their life.
16 The committee also felt that advance care planning should not be restricted to
17 planning for possible future loss of mental capacity.

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

22 **How the recommendations might affect services**

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

26 Advance care planning supports adults approaching the end of their life to be cared
27 for in their preferred place, which is often in the community. This may reduce the
28 need for hospital services but increase demand for services in the community. The
29 advance care plan documents the person's current, future and emergency needs,

1 improving coordination of care across the multipractitioner team and should help
2 avoid unnecessary hospital attendances and admissions.

3 Full details of the evidence and the committee's discussion are in the following
4 [evidence reviews](#):

- 5 • C: barriers to accessing end of life care services
- 6 • F: advance care planning
- 7 • G: involving carers.

8 [Return to recommendations](#)

9 ***Reviewing needs***

10 [Recommendation 1.7.1](#)

11 **Why the committee made the recommendation**

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

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

25 **How the recommendation might affect services**

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

1 Full details of the evidence and the committee's discussion are in the following
2 [evidence reviews](#):

- 3 • C: barriers to end of life care services
- 4 • G: involving carers
- 5 • J: identifying the need for additional services; timing and frequency of review of
6 services.

7 [Return to recommendations](#)

8 ***Communicating and sharing information between services***

9 [Recommendations 1.8.1 to 1.8.4](#)

10 **Why the committee made the recommendations**

11 The committee agreed that electronic information systems should be used because
12 they would be the most effective and efficient method to share information. However,
13 the evidence was too limited for the committee to recommend a particular system.

14 The committee developed a research recommendation to encourage further
15 research in this area (see [research recommendation 2](#)).

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

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

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

1 **How the recommendations might affect services**

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

10 Full details of the evidence and the committee's discussion are in [evidence review 1:](#)
11 [information sharing](#).

12 [Return to recommendations](#)

13 ***Providing multipractitioner care***

14 [Recommendations 1.9.1 and 1.9.2](#)

15 **Why the committee made the recommendations**

16 The evidence showed that a multipractitioner approach to care was favourable and
17 had a positive impact on supporting adults to stay in their preferred place of care.
18 The committee agreed that the skills and expertise of many specialities and
19 disciplines is needed to meet people's varied and changing needs. However, there is
20 no clear evidence on the ideal composition of a multipractitioner team and so instead
21 of identifying specific roles the committee set out the type of support people may
22 need access to as they approach the end of their life.

23 **How the recommendations might affect services**

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

1 Full details of the evidence and the committee's discussion are in the following
2 [evidence reviews](#):

- 3 • E: multiprofessional team
- 4 • L: additional services.

5 [Return to recommendations](#)

6 ***Providing end of life care coordination***

7 [Recommendations 1.10.1 to 1.10.3](#)

8 **Why the committee made recommendation 1.10.1**

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

14 The committee agreed that good coordination of care and effective communication
15 systems are especially important when people have contact with multiple services
16 and organisation.

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

20 **How this recommendation might affect services:**

21 The recommendation reflects current good practice available in some services, but
22 there is variation nationally. In areas where good coordination of care is lacking, it
23 should result in more efficient service provision and help to minimise crises and
24 support people to stay in their preferred place of care. Good care coordination
25 should also reduce the use of unnecessary services and avoid duplication of care.

26 Full details of the evidence and the committee's discussion are in the following
27 [evidence reviews](#):

- 28 • C: barriers to accessing end of life care services

- 1 • G: involving carers.

2 **Why the committee made recommendations 1.10.2 and 1.10.3**

3 The evidence showed that having someone to organise care was of some benefit,
4 particularly in reducing unscheduled and emergency hospital visits and admissions.
5 However, it was not clear if this should be a specific role or who should do this.
6 Therefore the committee listed the key principles within end of life care coordination
7 that community, hospital and hospice services could provide in collaboration rather
8 than specifying who should take on this role and where it should be located.

9 **How these recommendations might affect services**

10 The recommendations reflect current good practice available in some services, but
11 there is variation nationally. Where good coordination of care is lacking, the
12 recommendations should result in more efficient service provision and help to
13 minimise crises and support people to receive personalised and planned care in their
14 preferred place. Care coordination by health and social care professionals is taking
15 place currently in the NHS but the committee was uncertain how extensively it is
16 practiced. Additional resources may be needed to coordinate care across services
17 and deliver the key roles of end of life care coordination, but it should help to reduce
18 the use of unnecessary services and avoid duplication of care.

19 Full details of the evidence and the committee's discussion are in the following
20 [evidence reviews](#):

- 21 • C: barriers to accessing end of life care services
22 • D: coordinator and lead health professional
23 • G: involving carers.

24 [Return to recommendations](#)

25 ***Transferring people between care settings***

26 [Recommendations 1.11.1 to 1.11.3](#)

27 **Why the committee made the recommendations**

28 There was very little evidence on transferring adults between settings when they are
29 approaching the end of their life. However, the committee agreed that the availability

1 of efficient and timely transfer is important to ensure that people can be moved
2 quickly to their preferred place of care when needed.

3 The committee also discussed the consequences of delayed transfer, which can
4 result in people staying in inappropriate care settings or being cared for and dying in
5 settings other than their preferred place of care. They also discussed how clear
6 communication and processes between services providing care and those providing
7 transport can help to avoid delays and enable efficient transfer.

8 The committee developed recommendations to reinforce good practice and support
9 the advice in NICE's guideline on [transition between inpatient hospital settings and](#)
10 [community or care home settings for adults with social care needs](#). The committee
11 also noted that more research is needed to determine the optimal service
12 configuration for transfer of people with different conditions and at different stages as
13 people approach the end of their life.(see [research recommendation 4](#)).

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

18 **How the recommendations might affect services**

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

23 Full details of the evidence and the committee's discussion are in the following
24 [evidence reviews](#):

- 25 • C: barriers to accessing end of life care services
- 26 • M: optimal transition and facilitating discharge.

27 [Return to recommendations](#)

1 ***Providing out-of-hours care***

2 [Recommendation 1.12.1](#)

3 **Why the committee made the recommendation**

4 The evidence for providing an out-of-hours service showed some benefit in
5 supporting people to stay in their preferred place of care. The committee agreed that
6 the services described in the studies reflected existing out-of-hours services in areas
7 of good practice. However, there was evidence that elements of service provision
8 important for people approaching the end of their life may be variable or lacking, so
9 these were the focus for the recommendation.

10 The evidence supported the committee's experience that access to healthcare
11 advice is critical in providing reassurance and ensuring people have access to the
12 services they need. The committee agreed that a healthcare practitioner should be
13 available at all times to provide this, and that they would need access to the person's
14 records and advance care plan, preferably through a shared electronic information
15 system, to enable them to make informed decisions about care.

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

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

24 An analysis of the evidence for providing a dedicated out-of-hours end of life care
25 advice line and an out-of-hours pharmacy service showed that the costs of providing
26 these services could be balanced by the savings incurred by a relatively small
27 reduction in emergency admissions and length of stay of admissions, and an
28 increase in the number of people remaining in the community. Therefore, the
29 committee agreed that these services would be a good use of NHS resources.

1 **How the recommendation might affect services**

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

10 Full details of the evidence and the committee's discussion are in the following
11 [evidence reviews](#):

- 12 • C: barriers to accessing end of life care services
- 13 • G: involving carers
- 14 • K: out-of-hours services.

15 [Return to recommendations](#)

16 **Context**

17 End of life care is defined by NHS England as care that is provided in the 'last year of
18 life'. After the Liverpool Care Pathway was withdrawn in 2014, a number of national
19 reports, guidelines and policy documents began to describe the changes needed for
20 a new approach to end of life care services. They identified that high-quality, timely,
21 compassionate and individualised care should be accessible to all those who need it.
22 To progress this intention the models of care and the service delivery arrangements
23 that need to be put in place for people as they approach the end of their life need to
24 be defined.

25 End of life care may be delivered by disease-specific specialists and their associated
26 teams; by generalists such as primary care teams or hospital-based generalists (for
27 example, elderly care); or by palliative care specialists in hospices, hospitals and
28 community settings. Giving this type of care can ensure that people live well until
29 they die. Care that is given alongside, and to enhance, disease-modifying and
30 potentially life-prolonging therapies, often for years, is called 'supportive care'.. Care

1 that is aimed primarily at giving comfort and maintaining quality of life in the last
2 months of life is commonly referred to as palliative care. Palliative care particularly
3 aims to provide relief from pain and other distressing symptoms, integrate the
4 psychological, social and spiritual aspects of the person's care, and continue to offer
5 a support system to help people to live as actively as possible until their death.

6 This guideline describes end of life care services for providing palliative and
7 supportive care to adults approaching the end of their life with any conditions and
8 diseases. It advises on service models for care in acute settings by disease-specific
9 specialists and their supportive services, or by primary care or specialists in palliative
10 care in the community (for example, hospices).

11 **Finding more information and resources**

12 To find out what NICE has said on topics related to this guideline, see our web page
13 on [end of life care](#).

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