NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE

Guideline scope

Supportive and palliative care: service delivery

Topic

The Department of Health in England has asked NICE to develop a service delivery guideline on supportive and palliative care in adults. This will update the NICE guideline on improving supportive and palliative care for adults with cancer and extend the population beyond adults with cancer, to cover adults with life-limiting conditions.

This guideline will update and replace the NICE guideline on improving supportive and palliative care for adults with cancer.

This guideline will also be used to update the NICE quality standard for end of life care.

For more information about why this guideline is being developed, and how the guideline will fit into current practice, see the context section.

Who the guideline is for

- Generalist healthcare professionals in primary and secondary care.
- Specialist healthcare professionals in primary and secondary care.
- Commissioners of supportive and palliative care services.
- Providers of supportive and palliative care services.
- Other practitioners delivering end of life care services.
- People using services, families and carers and the public.

It may also be relevant for:

- Organisations in the charitable sector delivering supportive and palliative care services.
- Providers of social care as part of supportive and palliative care services.

NICE guidelines cover health and care in England. Decisions on how they apply in other UK countries are made by ministers in the Welsh Government, Scottish Government, and Northern Ireland Executive.

Equality considerations

NICE has carried out an equality impact assessment during scoping. The assessment:

- lists equality issues identified, and how they have been addressed
- explains why any groups are excluded from the scope.

The guideline will look at inequalities relating to the groups listed below that need special consideration to ensure they have equal opportunities to access services.

- People with dementia.
- People with cognitive impairment.
- People with learning disabilities.
- Homeless people.

Definitions

Definitions for the following terms that will be used by the guideline are provided in the table below:

Term	Definition
Supportive care	Care that helps the person and people important to them to cope with life-limiting illness and its treatment – from before diagnosis, through diagnosis and treatment, to cure or continuing illness, or death and bereavement.
Palliative care	Care towards the end of life that aims to provide relief from pain and other distressing symptoms, integrate the psychological and spiritual aspects of the person's care, and provide a support system that allows people to live as actively as possible until their death.
Non-specialist palliative care	Palliative care provided by healthcare professionals within their normal duties, and without specialist knowledge, skills and competence in palliative care.
Specialist palliative care	Palliative care provided at the expert level, by a trained multi-professional team (including, for example, consultants in palliative medicine and clinical nurse specialists in palliative care), who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams.

1. What the guideline is about

1.1 Who is the focus?

Groups that will be covered

- Adults (over 18) with life-limiting conditions.
- Health and care professionals delivering supportive and palliative care to NHS patients.
- Carers and/or those important to people accessing supportive and palliative care.

1.2 Settings

Settings that will be covered

- All settings where NHS care is provided or commissioned.

Settings that will not be covered

- Supportive and palliative care services commissioned and provided without any element of NHS funding.

1.3 Activities, services or aspects of care

Key areas that will be covered

1 Holistic needs assessment.

- Using established tools (for example the Sheffield Profile for Assessment and Referral for Care (SPARC), the distress thermometer and the 'pepsi cola' aide memoire[1]) to identify the supportive care and palliative care needs of the person, carers and those important to them, including:
  - physical functioning
  - social wellbeing
  - psychological and emotional wellbeing
  - cognitive functioning
  - sexual functioning (and/or 'wellbeing')
  - spiritual wellbeing and cultural and religious needs.

2 Service organisation for supportive care.

- Planning and coordinating services.
- Service delivery models, including those covering both acute and community settings.
- 24/7 provision of care and access to specialist services.
- Transitional care for young adults (aged 18-25) moving from children's supportive care services to adult supportive care services.

3 Service organisation for palliative care.

- Planning and coordinating services.
- Service delivery models for palliative and end of life care.
- 24/7 provision of care including access to specialist services.

[1] Holistic checklist pepsi cola aide memoire © 2014 Used under licence by the Gold Standards Framework CIC, amended from original Oct 2014

- Identification and referral of people at risk of complex bereavement.
- Transitional care for young adults (aged 18-25) moving from children's palliative care services to adult palliative and end of life care services.

Areas from the published guideline that will be updated

1. Co-ordination of care.
2. Psychological support services.
3. Spiritual support services.
4. General palliative care services
5. Rehabilitation services.
6. Specialist palliative care services.
7. Services for families and carers, including bereavement care.

Areas not in the published guideline that will be included in the update

1. Transitional care for young adults (aged 18-25) moving from children's services to adult services.
2. The role of holistic needs assessment to identify the supportive and palliative care needs of the person, carers and those important to them.
3. Sharing information between multiprofessional teams.

Areas that will not be covered

1. Clinical aspects of care.
2. Education and training.

Areas from the published guideline that will be removed

1. Complementary therapy services.
2. Research in supportive and palliative care: current evidence and recommendations for direction and design of future research.
3. User involvement in planning, delivering and evaluating services.
4. Face-to-face communication.
5. Social support services.
6. Information.

Areas not covered by the published guideline or the update

1. Condition-specific holistic needs assessment tools.

2 Specific management related to the clinical care of individual conditions at the end of life.

Recommendations in areas that are not being updated may be edited to ensure that they meet current editorial standards, and reflect the current policy and practice context.

1.4 Economic aspects

We will take economic aspects into account when making recommendations. We will develop an economic plan that states for each review question (or key area in the scope) whether economic considerations are relevant, and if so whether this is an area that should be prioritised for economic modelling and analysis. We will review the economic evidence and carry out economic analyses, using an NHS and personal social services (PSS) perspective, as appropriate.

1.5 Key issues and questions

While writing this scope, we have identified the following key issues, and key questions related to them:

1 Holistic needs assessment

1.1. What is the best tool to identify and assess holistic needs for supportive care in people with life-limiting conditions?

1.2 What is the best tool to identify and assess holistic needs for palliative care in people with life-limiting conditions?

1.3 What is the best tool to identify and assess holistic needs for supportive care in carers and those who are important to people with life-limiting conditions?

1.5 When and how often should supportive care needs be reviewed in people with life-limiting conditions?

1.6 When and how often should palliative care needs be reviewed in people with life-limiting conditions?

1.7 When and how often should supportive care needs be reviewed in carers and those who are important to people with life-limiting conditions?

2 Service organisation for supportive care

2.1 What is the best model for planning supportive care services?

2.2 What is the best model for coordinating supportive care services?

2.3 What is the best way to share information between multiprofessional teams to ensure continuity of supportive care services?

2.3 Where should supportive care services be delivered (for example, in the community, at home or in acute hospitals)?

2.4 Who should provide supportive care services and how should these services be configured (for example, the organisation of the multiprofessional team)?

2.5 When should supportive care services be provided and how should they be accessed?

2.6 What types of supportive services, including specialist palliative care, should be available, and what is the minimum level needed, to deliver unplanned 24/7 care?

3 Service organisation for palliative care

3.1 What is the best model for planning palliative care services?

3.2 What is the best model for coordinating palliative care services?

3.3 What is the best way to share information between multiprofessional teams to ensure continuity of palliative care services?

3.4 Where should palliative care services be delivered (for example, in the community, at home or in acute hospitals)?

3.5 Who should provide palliative care services and how should these services be configured (for example the organisation of the multiprofessional team)?

3.6 When should palliative care services be provided and how should they be accessed?

3.7 What types of non-specialist palliative and specialist palliative care services should be available, and what is the minimum level needed, to deliver unplanned 24/7 care?

3.8 How should young adults moving from children's to adults' palliative and end of life services be supported?

The key questions may be used to develop more detailed review questions, which guide the systematic review of the literature.

1.6 Main outcomes

The main outcomes that will be considered when searching for and assessing the evidence are:

1. Patient-reported outcomes.
2. Views and satisfaction of those receiving supportive and palliative care and those important to them.
3. Health-related quality of life.
4. Preferred and actual place of care.
5. Preferred and actual place of death.
6. Staff satisfaction among providers of supportive and palliative care.
7. Resource use and costs, including length of hospital stay, number of hospital visits and use of community-based services.

2 Links with other NICE guidance, NICE quality standards, and NICE Pathways

2.1 NICE guidance

NICE guidance that will be updated by this guideline

- Improving supportive and palliative care for adults with cancer (2014) NICE guideline CSG4

NICE guidance about the experience of people using NHS services

NICE has produced the following guidance on the experience of people using the NHS. This guideline will not include additional recommendations on these topics unless there are specific issues related to supportive and palliative care:

- Patient experience in adult NHS services (2012) NICE guideline CG138
- Service user experience in adult mental health (2011) NICE guideline CG136
- Medicines adherence (2009) NICE guideline CG76

NICE guidance in development that is closely related to this guideline

NICE is currently developing the following guidance that is closely related to this guideline:

- Motor neurone disease. NICE guideline. Publication expected February 2016.
- Transition from children's to adults' services. NICE guideline. Publication expected February 2016.
- Major trauma. NICE guideline. Publication expected February 2016.
- Transition between inpatient mental health settings and community and care home settings for people with social care needs. NICE guideline. Publication expected August 2016.
- Older people with social care needs and multiple long-term conditions. Quality Standard. Publication expected September 2016.

- Acute medical emergencies in adults and young people, service guidance. NICE guideline. Publication expected November 2016.
- End of life care for infants, children and young people. Publication date to be confirmed.

2.2 NICE quality standards

NICE quality standards that may need to be revised or updated when this guideline is published

- End of life care for adults. (2011) NICE quality standard 13.
- Dementia: independence and wellbeing. (2013) NICE quality standard 30.
- Breast cancer. (2011) NICE quality standard 12.
- Chronic obstructive pulmonary disease. (2011) NICE quality standard 10.
- Dementia: support in health and social care. (2010) NICE quality standard.

2.3 NICE Pathways

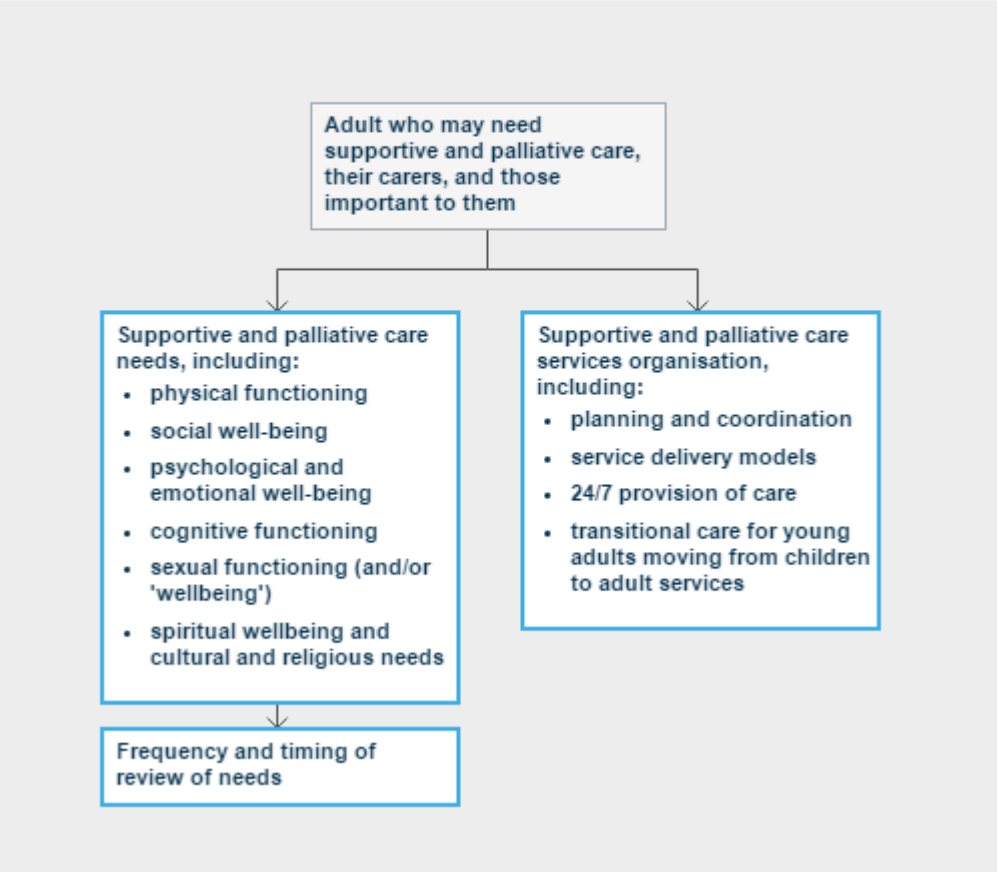
When this guideline is published, the recommendations will be added to NICE Pathways. NICE Pathways bring together all related NICE guidance and associated products on a topic in an interactive, topic-based flow chart.

A draft pathway outline on how to improve supportive and palliative care, based on the draft scope, is included below. It will be adapted and more detail added as the recommendations are written during guideline development.

The NICE Pathway will also include links to:

- Care of dying adults in the last days of life. NICE guideline NG31 (2015)
- End of life care for adults. NICE quality standard 13 (2011)
- the NICE pathway on opioids for pain relief in palliative care

Supportive and palliative care overview



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3 Context

While end of life care is defined by NHS England as care that is provided in the 'last year of life', it is recognised that many people need this type of care long before the last 12 months of life. After the Liverpool Care Pathway was withdrawn in 2014, a number of national reports and policy documents began to describe the changes needed for a new approach to end of life care services. High-quality, timely and compassionate care should be accessible to all those who need it. There is a need to identify and standardise the supportive and palliative care that is needed for people with life-limiting diseases as they approach the end of their life, as well as the service delivery arrangements that need to be put in place.

In the NICE guideline on improving supportive and palliative care for adults with cancer, published in 2004, the term 'supportive care' was used for the first time in the context of cancer management. The guideline defines supportive care as care that 'helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement'. This definition can be applied to conditions other than cancer, although it may be less well understood or applied in other conditions. Supportive care is not related to the patient's condition or prognosis, rather to the needs of the person and those important to them.

Palliative care aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person's care, and offer a support system to help people to live as actively as possible until their death. The 2004 guideline defined palliative care as 'the active holistic care of patients with advanced, progressive illness'. It recommended that palliative care should be applied early in the course of illness alongside investigations and therapies intended to prolong life (such as chemotherapy in the case of cancer). In practice palliative care is restricted to the last months and weeks of life, while supportive care covers the earlier stages of progressive illness; and for people with cancer, it now extends to the care of long-term survivors.

That NICE guideline helped to establish for the first time, a comprehensive approach to supporting people with cancer and those important to them, from the first moment of diagnosis, through treatment aimed at curing or managing the cancer, into the advanced stages and finally into end of life care. The 2004 guideline will be replaced by a new service delivery guideline, which extends the population beyond cancer to other conditions, but maintains the focus on both supportive and palliative care.

3.1 Key facts and figures

Approximately 470,000 people die in England every year, Estimates suggest that of these, 355,000 people need palliative care. Currently, approximately 171,000 people receive specialist palliative care. Little data exists on the numbers needing supportive care, although it is likely to be a much larger number, because it includes the needs of people living with life-limiting conditions and those who have had cancer. In 2015, supportive and palliative care services are focused on people with cancer and those important to them. Many palliative care services, including hospices run by the charitable sector, have started to provide care for more people who do not have cancer; however, these tend to be people in the last months or weeks of life of the certain disease groups, which haven’t changed since 2004. In the present health and social care context, many other diseases of the ageing population are placing increasing demands on over-burdened primary care and hospital services and, in these areas, palliative care service provision is patchy and selective. For example, very few people with dementia are admitted to palliative care services. If they also have cancer or another 'terminal' condition they may be eligible, but only in the very last stage of disease. Other conditions such as Parkinson's disease and rheumatic and degenerative conditions, which can involve severe pain as well as causing psychological and social problems for families, are under-served.

In addition to older people, there are other groups that are not receiving care from supportive and palliative care services. For example, sickle cell disease is very common in people of African-Caribbean or Middle Eastern origin. This condition causes severe chronic pain as well as acute exacerbations of pain,

and causes psychological, social and cultural problems. However, it is rare for palliative care services to provide support or even advice for managing sickle cell disease to haematology services. Identifying the needs and support requirements of people providing care to these overlooked groups is a priority.

3.2 Current practice

Although the NICE guidance on improving supportive and palliative care for adults with cancer (2004) was focused on supporting people with cancer, it has been applied in practice to groups of patients diagnosed with certain other conditions, especially in settings in which palliative care services are already very involved, such as hospices. These conditions include advanced neurological conditions, such as motor neurone disease and multiple sclerosis; and end stage pulmonary, cardiac and renal disease.

The provision of supportive care for people with cancer and those important to them still varies geographically, and is mainly confined to large teaching hospital trusts where hospital-based palliative care teams are more integrated with oncology and haemato-oncology services (to a lesser extent). The equity of service delivery and organisation of supportive care for people with conditions other than cancer is worse.

Clear guidance is needed on providing more equitable and consistent supportive and palliative care for all people with chronic and progressive diseases, not just those with cancer and not just in the last year of life. Supportive care provision should be based on individual needs, not the stage of disease or prognosis, determined by consistent and comprehensive holistic needs assessment. There is a need to define who should provide these services wherever NHS funding is received, including the role of 'specialist' palliative care services.

3.3 Policy, legislation, regulation and commissioning

Commissioning

Commissioning guidance for specialist palliative care (National Council for Palliative Care 2012) set out the factors that commissioners need to consider

when commissioning specialist palliative care and includes useful sources of information and data, information on starting to measure value and impact, and some early evidence of the potential for cost reduction and cost avoidance. The guideline, where appropriate, will use sources of data and models for commissioning services outlined in this document.

4 Further information

This is the draft scope for consultation with registered stakeholders. The consultation dates are 31 December 2015 to 29 January 2016.

The guideline is expected to be published in January 2018.

You can follow progress of the guideline.
http://www.nice.org.uk/guidance/indevelopment/gid-cgwave0799

Our website has information about how NICE guidelines are developed.