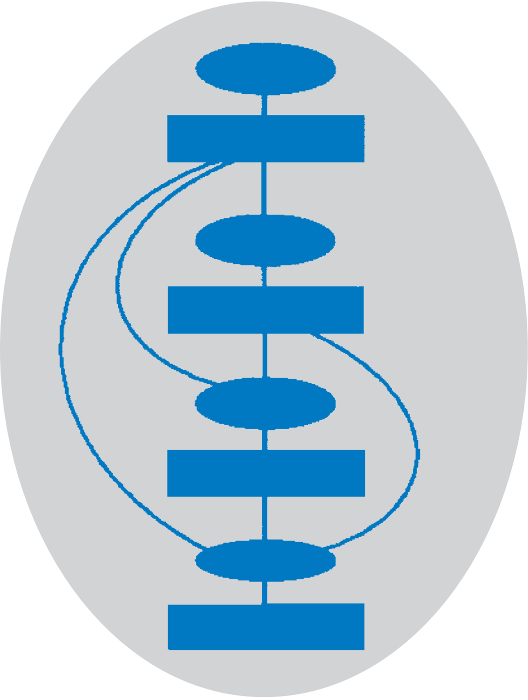
NHS

National Institute for
Clinical Excellence

Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

Executive Summary



Improving Supportive and Palliative Care for Adults with Cancer

Cancer service guidance supports the implementation of *The NHS Cancer Plan* for England,[1] and the NHS Plan for Wales *Improving Health in Wales.*[2] The service guidance programme was initiated in 1995 to follow on from the Calman-Hine Report, *A Policy Framework for Commissioning Cancer Services.*[3] The focus of the cancer service guidance is to guide the commissioning of services and is therefore different from clinical practice guidelines. Health services in England and Wales have organisational arrangements in place for securing improvements in cancer services and those responsible for their operation should take this guidance into account when planning, commissioning and organising services for cancer patients. The recommendations in the guidance concentrate on aspects of services that are likely to have significant impact on health outcomes. Both the objectives and resource implications of implementing the recommendations are considered. This guidance can be used to identify gaps in local provision and to check the appropriateness of existing services.

References

1. Department of Health (2001) *The NHS Cancer Plan.* Available from: www.doh.gov.uk/cancer/cancerplan.htm
2. National Assembly for Wales (2001) *Improving Health in Wales: A Plan for the NHS and its Partners.* Available from: www.wales.gov.uk/healthplanonline/health_plan/content/nhsplan-e.pdf
3. *A Policy Framework for Commissioning Cancer Services*: *A Report by the Expert Advisory Group on Cancer to the Chief Medical Officers of England and Wales* (1995). Available from: www.doh.gov.uk/cancer/pdfs/calman-hine.pdf

This guidance is written in the following context:
This guidance is a part of the Institute's inherited work programme. It was commissioned by the Department of Health before the Institute was formed in April 1999. The developers have worked with the Institute to ensure that the guidance has been subjected to validation and consultation with stakeholders. The recommendations are based on the research evidence that addresses clinical effectiveness and service delivery. While cost impact has been calculated for the main recommendations, formal cost-effectiveness studies have not been performed.

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Copies of this document can be obtained from the NHS Response Line by telephoning 0870 1555455 and quoting reference N0477. Bilingual information for the public has been published, reference N0476, and a CD with all documentation including the research evidence on which the guidance is based is also available, reference N0475.

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Introduction

ES1 Over 230,000 people in England and Wales develop cancer each year, and cancer accounts for one quarter of all deaths. A diagnosis of cancer and its subsequent treatment can have a devastating impact on the quality of a person's life, as well as on the lives of families and other carers. Patients face new fears and uncertainties and may have to undergo unpleasant and debilitating treatments. They and their families and carers need access to support from the time that cancer is first suspected, through all stages of treatment to recovery or, in some cases, to death and into bereavement.

ES2 Studies have consistently shown that, in addition to receiving the best treatments, patients want to be treated as individuals, with dignity and respect, and to have their voices heard in decisions about treatment and care. Most patients want detailed information about their condition, possible treatments and services. Good face-to-face communication is highly valued. Patients expect services to be of high quality and to be well co-ordinated. Should they need it, they expect to be offered optimal symptom control and psychological, social and spiritual support. They wish to be enabled to die in the place of their choice, often their own home. They want to be assured that their families and carers will receive support during their illness and, if they die, following bereavement.

ES3 Although many patients report positively on their experience of cancer care, there are still too many who claim they did not receive the information and support they needed. The first National Cancer Patient Survey[1] showed wide variations in the quality of care delivered across the country.

ES4 Patients' needs for supportive and palliative care may not be met for several reasons. Services from which they might benefit may not be universally available. Even when services are available, patients' needs may go unrecognised by professionals, who consequently do not offer referral. Poor inter-professional communication and co-ordination can lead to suboptimal care.

This Guidance: aims, development and implementation

ES5 This Guidance defines service models likely to ensure that patients with cancer, with their families and carers, receive support and care to help them cope with cancer and its treatment at all stages.

ES6 The Guidance is intended to complement the series of *Improving Outcomes* guidance manuals on specific cancers. As with these manuals, its recommendations should not be viewed as clinical guidelines, and indications for specific clinical interventions (such as for pain control) have not been evaluated. Although focused solely on services for adult patients with cancer and their families, it may inform the development of service models for other groups of patients.

ES7 The approach used to develop the Guidance is similar to that adopted for site-specific guidance manuals. The views of a wide range of professionals and service users were canvassed at each step of the process. Proposals were critically appraised in the light of research evidence. An Editorial Board then prepared draft Guidance, made available for consultation through the National Institute for Clinical Excellence (NICE).

ES8 The Guidance sets out recommendations on each issue of importance to patients and carers, as listed in paragraph ES2. Some recommendations can best be taken forward at national level by the Department of Health and the National Assembly for Wales. Most of the recommendations, however, will require concerted action from Cancer Networks, commissioners, Workforce Development Confederations (the Workforce Development Steering Group in Wales), provider organisations, multidisciplinary teams and individual practitioners.

ES9 *The NHS Plan*[2] for England set out the intention to make available authoritative guidance on all aspects of cancer care. *The NHS Cancer Plan*[3] made it clear that the NHS is expected to implement the recommendations in guidance manuals, re-emphasised in the Planning and Priorities Guidance issued in December 2002. *Improving Health in Wales*[4] described how strategies for achieving health gain targets are underpinned by national standards of care set through National Service Frameworks and guidance produced by NICE. All services providing care to people with cancer are expected to be able to show that they meet these standards.

ES10 Some recommendations in the Guidance build on existing good practice and should be acted on as soon as possible. Other recommendations, particularly those that require training and appointment of additional staff, will inevitably take longer.

ES11 It is anticipated that the recommendations will promote clinical governance through incorporation into national cancer standards that will enable the quality of supportive and palliative care services to be monitored through quality assurance programmes (such as the peer review appraisal programme in England). Peer review programmes currently involve secondary and tertiary service providers in the NHS. The Department of Health and the National Assembly for Wales will need to consider how best to assure the quality of services provided in primary care and the voluntary sector.

ES12 Audits of the outcome of supportive and palliative care delivery will need to be developed. The National Cancer Patient Survey[1] could form a basis for this.

ES13 The relative paucity of research evidence on many key topic areas is discussed in more detail in Topic 13, *Research in Supportive and Palliative Care: current evidence and recommendations for direction and design of future research.* It is strongly recommended that further research be targeted at gaps identified through this process.

Overview of the service model

ES14 The Guidance is based on a service model involving Cancer Networks as the vehicle for delivery of the Cancer Plan. Cancer Networks are partnerships of organisations (both statutory and voluntary) working to secure the effective planning, delivery and monitoring of cancer services, including those for supportive and palliative care. They provide the framework for developing high quality services by bringing together relevant health and social care professionals, service users and managers.

ES15 The service model recognises:

- individual patients have different needs at different phases of their illness, and services should be responsive to patients' needs
- families and carers need support during the patient's life and in bereavement

- the central role of families and other carers in providing support to patients
- the importance of primary and community services, as patients spend most of their time living in the community
- the needs of some patients for a range of specialist services
- the importance of forging partnerships between patients and carers and health and social care professionals to achieve best outcomes
- the value of partnership in achieving effective multi-agency and multidisciplinary team working
- the value of patient and carer-led activities as an integral part of cancer care
- service users' value in planning services
- the importance of care for people dying from cancer
- the need for services to be ethnically and culturally sensitive, to take account of the needs of those whose preferred language is not English or Welsh, and to be tailored to the needs of those with disabilities and communication difficulties
- the value of high quality information for patients and carers.

Co-ordination of care

ES16 Lack of co-ordination between sectors (for instance, hospital and community) and within individual organisations has repeatedly been viewed as a problem in studies of patients' experience. Action is needed from Cancer Networks, provider organisations and multidisciplinary teams. Individual practitioners will also need to ensure they have the skills to assess patients' needs for support and information, a prerequisite for the delivery of co-ordinated care.

- **<u>Key Recommendation 1</u>: Within each Cancer Network, commissioners and providers (statutory and voluntary) of cancer and palliative care services, working with service users, should oversee the development of services in line with the recommendations of this Guidance. Key personnel will need to be identified to take this forward.**

- **Key Recommendation 2: Assessment and discussion of patients' needs for physical, psychological, social, spiritual and financial support should be undertaken at key points (such as at diagnosis; at commencement, during, and at the end of treatment; at relapse; and when death is approaching). Cancer Networks should ensure that a unified approach to assessing and recording patients' needs is adopted, and that professionals carry out assessments in partnership with patients and carers.**

- **Key Recommendation 3: Each multidisciplinary team or service should implement processes to ensure effective inter-professional communication within teams and between them and other service providers with whom the patient has contact. Mechanisms should be developed to promote continuity of care, which might include the nomination of a person to take on the role of 'key worker' for individual patients.**

User involvement

ES17 People whose lives are affected by cancer can make significant contributions to the planning, evaluation and delivery of services. They can also help other people affected by cancer through sharing experiences and ways of managing the impact of cancer on their lives. Time, cost and training issues need to be addressed so that patients and carers can participate fully.

- **Key Recommendation 4: Mechanisms should be in place to ensure the views of patients and carers are taken into account in developing and evaluating cancer and palliative care services. Cancer Partnership Groups[5] provide one potential mechanism. Systems should be devised to support patients and carers to participate in their own care, featuring a range of informal support opportunities such as self-help activities and peer support schemes within community settings.**

Face-to-face communication

ES18 Good face-to-face communication between health and social care professionals and patients and carers is fundamental to the provision of high quality care. It enables patients' concerns and preferences to be elicited and is the preferred mode of information-giving at critical points. Yet patients and carers frequently report communication skills of practitioners to be poor.

- **Key Recommendation 5: Communicating significant news should normally be undertaken by a senior clinician who has received advanced level training and is assessed as being an effective communicator. As this is not always practical, all staff should be able to respond appropriately to patients' and carers' questions in the first instance before referring to a senior colleague.**

- **Key Recommendation 6: The outcome of consultations in which key information is discussed should be recorded in patients' notes and communicated to other professionals involved in their care. Patients should be offered a permanent record of important points relating to the consultation.**

Information

ES19 Patients and carers cannot express preferences about care and make choices on involvement in decision making unless they have access to appropriate and timely information. Many patients report, however, that they receive inadequate information from health and social care professionals. Information materials of high quality should be available in places where patients can access them readily, with patients being offered them at key stages in the patient pathway.

- **Key Recommendation 7: Policies should be developed at local (Cancer Network/provider organisation/team) level detailing the information materials to be routinely offered at different stages to patients with particular concerns. These policies should be based on mapping exercises involving service users.**

- **Key Recommendation 8: Commissioners and provider organisations should ensure that patients and carers have easy access to a range of high quality information materials about cancer and cancer services. These materials should be free at the point of delivery and patients should be offered appropriate help to understand them within the context of their own circumstances.**

Psychological support services

ES20 Psychological distress is common among people affected by cancer and is an understandable response to a traumatic and threatening experience. Patients draw on their own inner resources to help them to cope and many derive emotional support from family and friends. Some patients, however, are likely to benefit from additional professional intervention because of the level and nature of their distress. In practice, psychological symptoms are often not identified and patients lack sufficient access to psychological support services.

- **Key Recommendation 9: Commissioners and providers of cancer services, working through Cancer Networks, should ensure that all patients undergo systematic psychological assessment at key points and have access to appropriate psychological support. A four-level model of professional psychological assessment and intervention is suggested to achieve this.**

Social support services

ES21 The social impact of cancer is considerable and can reach beyond the patient and immediate family. Patients may need: support to preserve social networks; support with personal care, cleaning and shopping; provision of care for vulnerable family members; advice on employment issues; and assistance in securing financial benefits. All such support may be provided informally or formally, in either a planned or reactive manner. Many patients and carers do not experience a coherent integrated system of social support.

- **Key Recommendation 10: Explicit partnership arrangements should be agreed between local health and social care services and the voluntary sector to ensure that the needs of patients with cancer and their carers are met in a timely fashion and that different components of social support are accessible from all locations.**

Spiritual support services

ES22 The diagnosis of life-threatening disease can raise unsettling questions for patients. Some people will seek to re-examine their beliefs, whether philosophical, religious or spiritual in nature. The needs of patients for spiritual support are, however, frequently unrecognised by health and social care professionals, who may feel uncomfortable broaching spiritual issues. Where care needs are recognised, there is often insufficient choice of people to whom patients can turn for spiritual care. Staff with a wide range of responsibilities in all settings should be sensitive to the spiritual needs of patients and carers, during life and after a patient's death.

- **Key Recommendation 11: Patients and carers should have access to staff who are sensitive to their spiritual needs. Multidisciplinary teams should have access to suitably qualified, authorised and appointed spiritual care givers who can act as a resource for patients, carers and staff. They should also be aware of local community resources for spiritual care.**

General palliative care services, including care of dying patients

ES23 Patients with advanced cancer require a range of services to ensure their physical, psychological, social and spiritual needs are met effectively and to enable them to live and die in the place of their choice, if at all possible. As clinical circumstances can change rapidly, these services need to be particularly well co-ordinated, and some need to be available on a 24-hour, seven days a week basis to prevent unnecessary suffering and unnecessary emergency admissions to hospital.

ES24 Much of the professional support given to patients with advanced cancer is delivered by health and social care professionals who are not specialists in palliative care and who may have received little training in this area. It is important to empower, enable, train and support such professionals to achieve the delivery of effective care.

- **Key Recommendation 12: Mechanisms need to be implemented within each locality to ensure that medical and nursing services are available for patients with advanced cancer on a 24-hour, seven days a week basis, and that equipment can be provided without undue delay. Those providing generalist medical and nursing services should have access to specialist advice at all times.**

- **Key Recommendation 13: Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed, and that the information is communicated within the team and with other professionals as appropriate. The *Gold Standards Framework*[6] provides one mechanism for achieving this.**

- **Key Recommendation 14: In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The *Liverpool Care Pathway for the Dying Patient*[7] provides one mechanism for achieving this.**

Specialist palliative care services

ES25 A significant proportion of people with advanced cancer experience a range of complex problems that cannot always be dealt with effectively by generalist services. In response, hospices and specialist palliative care services have been established across the country over the past three decades.

ES26 Access to and availability of specialist palliative care services is variable throughout the country. Many hospitals do not have full multidisciplinary teams who can provide advice on a 24-hour, seven days a week basis. Community specialist palliative care services vary considerably in their ability to provide services at weekends and outside normal working hours. The number of specialist palliative care beds per million population varies widely between Cancer Networks.

- **Key Recommendation 15: Commissioners and providers, working through Cancer Networks, should ensure they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should, as a minimum, include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be able to provide support to patients in their own homes, community hospitals and care homes.**

Rehabilitation services

ES27 Cancer and its treatment can have a major impact on a patient's ability to carry on with his or her usual daily routines. Activities most people take for granted, such as moving, speaking, eating, drinking and engaging in sexual activity, can be severely impaired. Cancer rehabilitation aims to maximise physical function, promote independence and help people adapt to their condition. A range of allied health professionals and other professionals provide rehabilitation services and, through developing self-management skills, patients can take an active role in adjusting to life with and after cancer.

ES28 Some patients are not getting access to rehabilitation services, either because their needs are unrecognised by front-line staff or because of a lack of allied health professionals who are adequately trained in the care of patients with cancer.

- **Key Recommendation 16: Commissioners and providers, working through Cancer Networks, should institute mechanisms to ensure that patients' needs for rehabilitation are recognised and that comprehensive rehabilitation services and suitable equipment are available to patients in all care locations. A four-level model for rehabilitation services is the suggested model for achieving this.**

Complementary therapy services

ES29 Decision making regarding the provision of complementary therapy services for patients with cancer is complex. A considerable proportion of patients express interest in these therapies, but there is little conventional evidence about their effectiveness for the relief of physical symptoms and psychological distress. This Guidance therefore focuses on the needs of patients to obtain reliable information to make decisions for themselves and on measures providers should take to ensure that patients can access these therapies safely, should they wish to do so.

- **Key Recommendation 17: Commissioners and NHS and voluntary sector providers should work in partnership across a Cancer Network to decide how best to meet the needs of patients for complementary therapies where there is evidence to support their use. As a minimum, high quality information should be made available to patients about complementary**

therapies and services. Provider organisations should ensure that any practitioner delivering complementary therapies in NHS settings conforms to policies designed to ensure best practice agreed by the Cancer Network.

Services for families and carers, including bereavement care

ES30 Families and carers provide essential support for patients, but their own needs for emotional and practical support may go unrecognised - often because they put the needs of the patient first. Families' and carers' needs for support can be particularly profound around the time of diagnosis, at the end of treatment, at recurrence, and most particularly around the time of death and bereavement. Professional support is not always available for families and carers who need it.

- **Key Recommendation 18: Provider organisations should nominate a lead person to oversee the development and implementation of services that specifically focus on the needs of families and carers during the patient's life and in bereavement, and which reflect cultural sensitivities.**

Workforce development

ES31 Many of the recommendations in this Guidance are critically dependent on workforce development - the appointment of additional staff and the enhancement of knowledge and skills of existing staff. Front-line staff require enhanced training in the assessment of patients' problems, concerns and needs; in information giving; and in communication skills. Additional specialist staff will be needed in roles related to information delivery, psychological support, rehabilitation, palliative care and support for families and carers.

- **Key Recommendation 19: Cancer Networks should work closely with Workforce Development Confederations (the Workforce Development Steering Group in Wales) to determine and meet workforce requirements and to ensure education and training programmes are available.**

- **Key Recommendation 20: Provider organisations should identify staff who may benefit from training and should facilitate their participation in training and ongoing development. Individual practitioners should ensure they have the knowledge and skills required for the roles they undertake.**

References

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