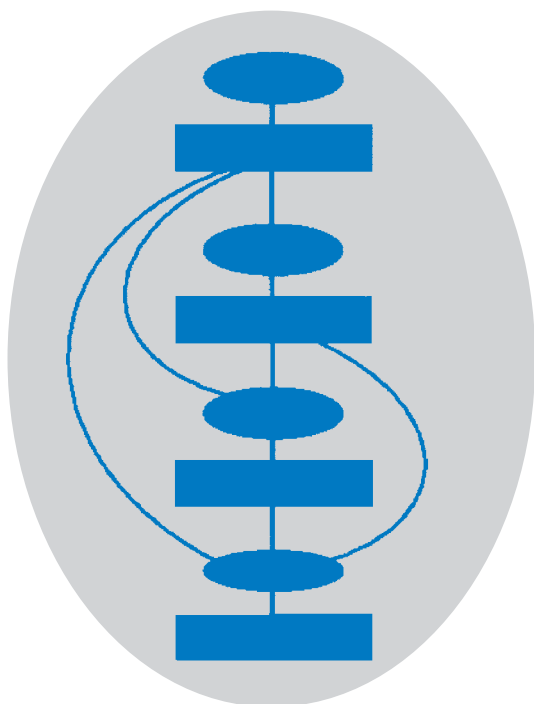


Guidance on Cancer Services

# Improving Supportive and Palliative Care for Adults with Cancer

The Manual



## **Update information**

In October 2019, NICE published a [guideline on end of life care for adults: service delivery](#), which should be read alongside this guideline. It includes recommendations that are relevant to this guideline, particularly to the sections on coordination of care and general palliative care services, including care of dying patients. Changes have also been made to remove some out-of-date references.

### Improving Supportive and Palliative Care for Adults with Cancer

Cancer service guidance supports the implementation of *The NHS Cancer Plan* for England,<sup>1</sup> and the NHS Plan for Wales *Improving Health in Wales*.<sup>2</sup> The service guidance programme was initiated in 1995 to follow on from the Calman-Hine Report, *A Policy Framework for Commissioning Cancer Services*.<sup>3</sup> 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](http://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](http://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](http://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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Guidance on Cancer Services

# Improving Supportive and Palliative Care for Adults with Cancer

The Manual

Retired: This guidance is retired which means it has no status and the health and care system is not expected to follow it.

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# Executive Summary

## 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<sup>1</sup> 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*<sup>2</sup> for England set out the intention to make available authoritative guidance on all aspects of cancer care. *The NHS Cancer Plan*<sup>3</sup> 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*<sup>4</sup> 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<sup>1</sup> 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.

- **Key Recommendation 1: 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<sup>5</sup> 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*<sup>6</sup> 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.

## 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.**

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# Introduction

## A. Aim of this Guidance

- I1 The aim of this Guidance is to define the service models needed to ensure that patients with cancer, their families and other carers receive support to help them cope with cancer and its treatment. Services may be needed at all stages of a patient's illness, from before formal diagnosis onward.

## B. Rationale for developing the Guidance

### **Burden of cancer**

- I2 Cancer affects a large number of people in England and Wales. Around a quarter of a million people are diagnosed with cancer each year, many of whom have family, close friends and carers who are also affected by the diagnosis. Even more people, probably well over a million, develop symptoms that could be due to cancer. These people and their families and carers may suffer significant levels of anxiety before they can be reassured that they do not have the disease.

### **What do patients and carers want and need?**

- I3 Research<sup>1,2</sup> has consistently shown that, in addition to receiving the best possible treatment, patients want and expect:
- to be treated as individuals, with dignity and with respect for their culture, lifestyles and beliefs
  - to have their voice heard, to be valued for their knowledge and skills and to be able to exercise real choice about treatments and services
  - to receive detailed high quality information about their condition and possible treatment, given in an honest, timely and sensitive manner at all stages of the patient pathway
  - to know what options are available to them under the NHS, voluntary and independent sectors, including access to self-help and support groups, complementary therapy services and other information

- to know that they will undergo only those interventions for which they have given informed consent
- to have good face-to-face communication with health and social care professionals
- to know that services will be well co-ordinated
- to know that services will be of high quality
- to know that their physical symptoms will be managed to a degree that is acceptable to them and is consistent with their clinical situation and clinicians' current knowledge and expertise
- to receive emotional support from professionals who are prepared to listen to them and are capable of understanding their concerns
- to receive support and advice on financial and employment issues
- to receive support to enable them to explore spiritual issues
- to die in the place of their choice
- to be assured that their family and carers will be supported throughout the illness and in bereavement.

### **Current service provision**

- I4 Although there is evidence of much good practice in the delivery of supportive care<sup>2</sup>, there is also extensive evidence that patients do not always receive the information and support they need at all steps in the patient pathway. The first National Cancer Patient Survey<sup>3</sup> showed wide variations in the quality of care across the country.

### **Why are patients' needs not always met?**

- I5 There are many reasons why needs remain unmet, each of which has to be addressed if outcomes are to be improved. They include:

- patients and carers being unaware of the existence of services that might help them
- professionals not eliciting patients' problems or concerns

- professionals being unaware of the potential benefits of existing services, and consequently not offering access or referral to them
- services demonstrated to be of benefit not being universally available
- poor co-ordination among professionals within a team or between services, leading to patients' needs not being addressed.

### **What needs to be done?**

I6 Evidence from surveys and other sources clearly suggests that services need to provide:

- improved assessment of the individual needs of people with cancer, including all the domains of physical, psychological, social and spiritual care
- better access to high quality information, including better 'signposting' of statutory and voluntary information and support services
- active promotion of self-help and support groups, recognising the large role played by people with cancer in managing their own care and the support sought from local and national voluntary organisations
- enhanced provision of supportive and palliative care services to meet current unmet needs and to reduce inequalities in service provision and access
- improved training for health and social care staff in providing supportive and palliative care
- better organisation, co-ordination and integration across Cancer Networks.

## **C. Definitions of supportive and palliative care**

I7 The understanding of supportive and palliative care on which this Guidance is based leans heavily on work by the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS).

## Supportive care

I8 The working definition of supportive care suggested by NCHSPCS is 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. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.’<sup>4</sup>

I9 Supportive care is provided to people with cancer and their carers throughout the patient pathway, from pre-diagnosis<sup>A</sup> onwards (Figure I.1). It should be given equal priority with other aspects of care and be fully integrated with diagnosis and treatment. It encompasses:

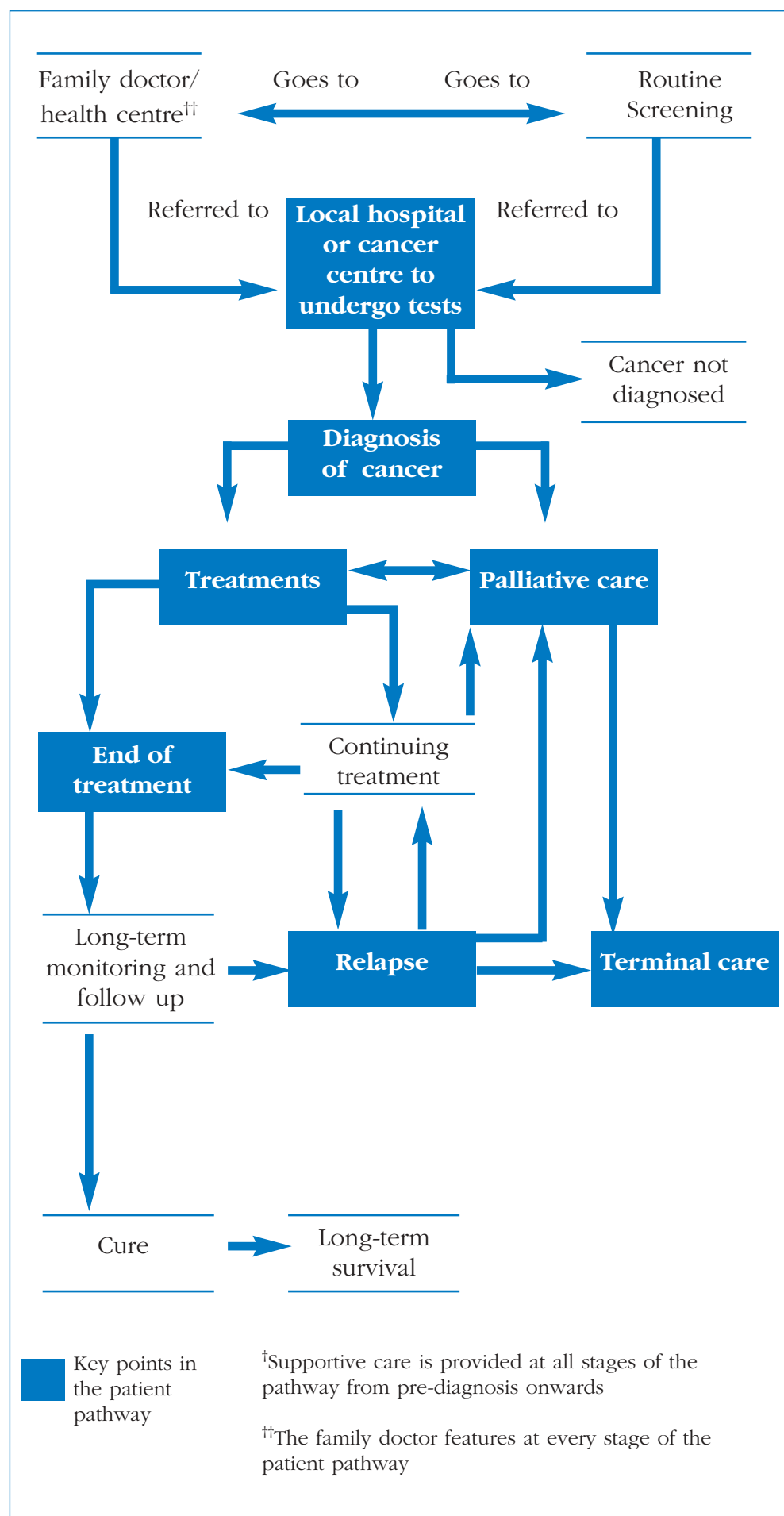
- self help and support
- user involvement
- information giving
- psychological support
- symptom control
- social support
- rehabilitation
- complementary therapies
- spiritual support
- palliative care
- end-of-life and bereavement care.

I10 Supportive care is an ‘umbrella’ term for all services, both generalist and specialist, that may be required to support people with cancer and their carers. It is not a response to a particular stage of disease, but is based on an assumption that people have needs for supportive care from the time that the possibility of cancer is first raised.

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<sup>A</sup> Patients and carers can have a range of problems prior to diagnosis when cancer is suspected, including anxiety and physical symptoms. These need to be managed appropriately, and patients should be enabled to access information at this point in the patient pathway if they wish it.

**Figure I.1 Map of patient pathway<sup>†</sup>**



- I11 Supportive care is not a distinct specialty, but is the responsibility of all health and social care professionals delivering care. It requires a spectrum of skills, extending from foundation skills to highly specific expertise and experience. Open and sensitive communication is important, as is good co-ordination between and within organisations and teams to ensure the smooth progression of patients from one service to another.

## **Palliative care**

- I12 Palliative care is:

‘...the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.’<sup>5</sup>

- I13 Palliative care is based on a number of principles, and aims to:

- provide relief from pain and other distressing symptoms
- integrate the psychological and spiritual aspects of patient care
- offer a support system to help patients to live as actively as possible until death and to help the family to cope during the patient’s illness and in their own bereavement
- be applied early in the course of illness in conjunction with other therapies intended to prolong life (such as chemotherapy or radiation therapy), including investigations to better understand and manage distressing clinical complications<sup>4,5</sup>.

- I14 It is now widely recognised that palliative care has a crucial role in the care received by patients and carers throughout the course of the disease and should be delivered in conjunction with anti-cancer and other treatments<sup>6</sup>. In the minds of patients, carers and some health and social care professionals, however, it tends to be associated with care for dying people<sup>2</sup>. This has significant implications for acceptability and access.

- I15 The professionals involved in providing palliative care fall into two distinct categories :



- those providing day-to-day care to patients and carers
- those who specialise in palliative care (consultants in palliative medicine and clinical nurse specialists in palliative care, for example), some of whom are accredited specialists<sup>4</sup>.

I16 Although palliative care encompasses many of the elements identified as 'supportive care', there are well-defined areas of expertise within specialist palliative care to which patients and carers may need access, such as interventions to respond to:

- unresolved symptoms and complex psychosocial issues for patients with advanced disease
- complex end-of-life issues
- complex bereavement issues.

I17 Importantly, both palliative and supportive care are often provided by patients' family and other carers, and not exclusively by professionals.

### **Supportive and palliative care services**

I18 Supportive and palliative care services should be delivered, as much as possible, where patients and carers want them – in the community (including a patient's own home, but also care homes and community hospitals), in hospital, or in a hospice.

I19 Patients, families and other carers should play the central role in making decisions about the care they receive. They may need support from health and social care professionals to help them to make decisions, to plan and evaluate their care, and to explore whether earlier decisions might need to be changed. User empowerment must therefore underpin good supportive and palliative care. Not all patients have close family and carers, however. Health and social care professionals should be sensitive to the needs of patients and be prepared to encourage their potential to contribute to their own care.

I20 A wide range of service providers is involved in delivering supportive and palliative care services, including those in primary care, secondary care and the voluntary and social sectors. Many work within multidisciplinary teams. Patients and carers also draw significant support from friends, family, support groups, volunteers and other community based non-statutory resources.

- I21 Providing supportive and palliative care should be an integral part of every health and social care professional's role, but for most, such care is likely to form only a small part of their workload. Many of these professionals are clearly 'generalists' in the field (general practitioners (GPs) and district nurses, for example), while others are specialists who may have received specific training and qualifications in supportive and/or palliative care or acquired substantial practical experience. These specialists, frequently dedicating all or most of their time to the care of people with cancer, include:
- site-specific cancer nurse specialists
  - cancer counsellors
  - cancer information nurses/other professionals
  - specialist allied health professionals
  - physicians in palliative medicine and palliative care nurse specialists.
- I22 For others, their 'generalist' or 'specialist' status will depend on the circumstances in which they work. A local authority social worker, for example, may be a generalist working with a wide range of clients, while a social worker employed by a hospice will be working as a specialist in palliative care.
- I23 Patients' needs tend to fluctuate across the patient pathway, and services should remain flexible to address changes during each person's experience of cancer. The relative contributions of those involved in supportive and palliative care, including the contributions of patients and carers, are also liable to change.

## D. Context, scope and organisation of the Guidance

### Context

- I24 The Guidance was commissioned by the Department of Health and Welsh Assembly Government as part of the *Improving Outcomes* series of cancer manuals, and follows on, in England, from the Calman-Hine report, *A Policy Framework for Commissioning Cancer Services*<sup>7</sup>, *The NHS Plan*<sup>8</sup> and *The NHS Cancer Plan*<sup>6</sup> and, in Wales, from *Improving Health in Wales*<sup>9</sup> and the Cameron Report, *Cancer Services in Wales*<sup>10</sup>.

- I25 It also reflects the outcomes of the Kennedy Inquiry<sup>11</sup>, which set out a number of recommendations on communication skills for health care professionals. In addition, it draws on the Commission for Health Improvement/Audit Commission report on cancer services<sup>2</sup> and the National Cancer Patient Survey<sup>3</sup> in England, both of which clearly identify issues that require urgent review and action.
- I26 *Shifting the Balance of Power: the next steps*<sup>12</sup> and *Improving Health in Wales: structural change for the NHS in Wales*<sup>13</sup> highlight the drive to develop networks of care. The reports set out the role of the 34 Cancer Networks in England and the three Cancer Networks in Wales in developing integrated care, improving clinical outcomes, providing cost-effective services, improving the experience of patients and carers and securing equity of service provision.
- I27 The Guidance forms a key element of the Supportive Care Strategy for England and is part of a series of initiatives designed to improve the experience of care. These initiatives include:
- the development of a Supportive and Palliative Care Co-ordinating Group
  - the development of the Cancer Information Strategy and establishment of the Coalition for Cancer Information<sup>14</sup>
  - the User Involvement Strategy, which led to a joint Department of Health/Macmillan Cancer Relief project to support user involvement in every Cancer Network
  - the New Opportunities Fund *Living with Cancer* initiative
  - Cancer Services Collaborative initiatives focused on improving patients' care experience and the community palliative care Gold Standards Framework Programme<sup>15, 16</sup>
  - the development of draft National Standards for Specialist Palliative Care for Cancer Services
  - a Department of Health-funded initiative for education and support for district and community nurses in every Cancer Network on the principles and practice of palliative care
  - the development of an accredited training programme in advanced communication skills training
  - the establishment of a National Partnership Group for specialist palliative care.

I28 Similar initiatives are under way in Wales, including:

- the establishment of the Wales Association of Palliative Care
- the development and publication of a strategy for palliative care services in Wales<sup>17</sup>
- the All-Wales Minimum Standards for specialist palliative care<sup>18B</sup>
- a Cancer Information Framework and the establishment of a Cancer Information Framework Project Board to oversee its implementation<sup>19</sup>
- the User and Carer Involvement Project, supported by Macmillan Cancer Relief and led by the South West Wales Cancer Network on behalf of the three Cancer Networks in Wales<sup>20</sup>
- measures to improve communication in health care and increase dissemination of health care information<sup>21</sup>.

## Scope

I29 This Guidance is intended to complement the site-specific guidance manuals in the *Improving Outcomes* series. While the site-specific manuals focus on services for patients with particular cancers, this Guidance reflects the common components of supportive and palliative care for *all* people with cancer and their carers. The Guidance does not attempt to review the effectiveness of individual technologies, such as interventions to control symptoms. Nor does it address issues that are general to the NHS rather than specific to cancer care, such as access to transport for patients and carers. The scope of the Guidance is shown in Box I.1.

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<sup>B</sup> To become the *All Wales Standards for Cancer* from March 2004.

## Box I.1 Scope of the Guidance

- The primary audience is those who commission supportive and palliative care services from the statutory and voluntary health and social care sectors, using NHS resources.
- The focus is on services commissioned in England and Wales in all settings in which care may be delivered, including services provided by non-NHS providers but commissioned by the NHS under service-level agreements.
- The Guidance concentrates on services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are acknowledged.
- While focused on services for patients with cancer and their carers, the Guidance may inform the development of service models for other groups of patients with similar needs.

I30 The following topic areas are covered:

- Co-ordination of care
- User involvement in planning, delivering and evaluating services
- Information
- Face-to-face communication
- Psychological support services
- Social support services
- Spiritual support services
- General palliative care services, including care of dying patients
- Specialist palliative care services
- Rehabilitation services
- Complementary therapy services
- Services for families and carers, including bereavement care
- Research in supportive and palliative care: current evidence and recommendations for direction and design of future research.

- I31 The order is intended to represent a logical sequence of issues, and does not reflect priorities.
- I32 The topic areas form a comprehensive package of care which, if fully implemented, will meet patients' and carers' needs. From their perspective, many elements are delivered simultaneously by one or more professionals or may be provided at different times over the course of their experience of cancer. For clarity of presentation, it is necessary to present the individual service components separately, despite the fact that they often overlap in practice. Key components of services are, however, defined to a degree sufficient to describe a competent and effective supportive and palliative care service.
- I33 The commissioning brief, drawn up by NICE, asked the Guidance Development Team whether a distinction could be drawn between 'core' and 'non-core' services. The Editorial Board gave careful consideration to this issue, and to whether levels of service could be quantified (for example, defining the number of needed beds per million population or the numbers of personnel necessary to provide services).
- I34 Given the nature of available evidence, it was concluded that while a range of services, including hospital and community palliative care teams and specialist in-patient facilities, is required in all parts of England and Wales, the requisite numbers of beds and staff cannot be determined due to different levels of need and demographic and geographical differences.
- I35 For other services, such as palliative day care services, the evidence suggests they can be provided in a number of ways, but does not allow any single way to be determined as essential. In, for example, complementary therapies, there is clear evidence of patients and carers appreciating these services, but much less clear evidence on their impact on outcomes. The strength of recommendations in the Guidance reflects these characteristics of the evidence.
- I36 The Guidance considers the needs for supportive and palliative care of all patients facing a diagnosis of cancer and their families and carers. It is recognised that specific groups of patients, however, will have differing levels of need. Older people, for example, are more likely to have existing illnesses and disabilities and may be living alone, and patients for whom English or Welsh is not their preferred language may have specific communication needs. Recommendations are based on the premise that if needs are properly assessed, they will be identified and addressed, irrespective of a person's age, gender or ethnicity.

- I37 The particular needs of young people with cancer are being addressed through NICE guidance on children and young people with cancer (see NICE website for details: <http://www.nice.org.uk>).

## **Organisation of the Guidance**

- I38 The Guidance is composed of three distinct sources: a Guidance Manual, the Research Evidence and the Economic Review. The topic areas are discussed in the same order for ease of cross-reference.

- I39 The Guidance Manual is based on all available sources of information. The Manual consists of:

- an executive summary, including key recommendations from all topic areas
- an introductory section
- thirteen topic areas, with recommended actions
- a summary of the main recommendations within the topic areas as they apply to:
  - A – national governments
  - B – commissioners
  - C – Cancer Networks
  - D – provider organisations
  - E – multidisciplinary teams/services
  - F – individual health and social care professionals
  - G – Workforce Development Confederations/the Workforce Development Steering Group in Wales
- appendices setting out how the Guidance was developed and people involved in the process
- a glossary.

- I40 Each topic area (with the exception of Topic 1, *Co-ordination of Care*, and Topic 11, *Complementary Therapy Services*) is organised in the same manner:

**Introduction** Highlights key issues for patients' needs for services and care in the topic area and provides a brief review of the limitations of current service provision.

**Objectives** A short statement of what the Guidance intends to achieve for patients and carers.

**Recommendations** Presented in three sections:

- *Overview* A summary of how services should be organised to achieve the objectives.
- *Service configuration and delivery* Specific recommendations about the service model and processes required to achieve the objectives.
- *Workforce development* The education, training and support needed by staff who deliver services.

**Research** Offers suggestions about the future direction of research and development, driven by clear gaps in knowledge and evidence of what service users want.

**Evidence** Sets out the evidence supporting the recommendations, arising from a review and critical appraisal of relevant research literature. The nature and reliability of the evidence is graded from A-C<sup>22</sup> throughout the document, as shown in Table I.1 (see Appendix 1 for details).

**Table I.1 Grading of reliability and quality of evidence supporting recommendations<sup>22</sup>**

<b>A</b>	Evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials.
<b>B</b>	Evidence from non-randomised controlled trials or observational studies.
<b>C</b>	Professional consensus.

**Resource implications** Provides an overview of the cost implications for the NHS of implementing the recommendations.



- I41 The Research Evidence is a condensed version of systematic reviews of research used to inform the Guidance, itself published in electronic format (see [www.nice.org.uk](http://www.nice.org.uk)) (see Appendix 1). It includes tables with information about individual studies and is fully referenced.
- I42 The Economic Review, in electronic format only, presents an analysis of the potential cost implications of the recommendations. It outlines the scope of the work and details methods used to arrive at cost estimates.
- I43 There is also an accompanying Public Version of the Guidance intended for patients and the wider public, which sets out a short summary of the key recommendations, and a stand-alone version of the Executive Summary.

## E. Methods and approaches to Guidance development

- I44 The Guidance is based, with some modifications, on an extensive, explicit and rigorous multi-stage process developed by the Chief Medical Officer's Cancer Guidance Group, chaired by Professor Haward of Leeds University. It also broadly adheres to processes set out by NICE in *The Guideline Development Process – An Overview for Stakeholders, the Public and the NHS*<sup>23</sup>, and *Guideline Development Methods – Information for National Collaborating Centres and Guideline Developers*<sup>24</sup>. A summary of the methods and approaches to the development of the Guidance is given in Appendix 1.
- I45 A wide range of individuals representing service users, professionals and policy-makers were involved in generating the Guidance, starting with proposals for recommendations which were then critically appraised in the light of research evidence. The Guidance Manual is drawn from material arising from a number of complementary activities, including a proposal-generating event, evidence review, guided discussion with commissioners and users and the deliberations of the Editorial Board (see Appendix 2.1 for membership).
- I46 The recommendations were underpinned by a framework depicting levels of service operation and providing defined reference points (Box I.2). The Summary of Recommendations sets out recommendations for action at each of these levels in relation to the main topic areas.

## Box I.2 Framework of levels of service operation used to underpin formulation of recommendations

- National level
- Commissioner level
- Cancer Network level
- Provider organisation level
- Team level\*
- Individual health and social care professional level

\*‘Teams’ refers to a wide range of professionals providing services to people with cancer in the statutory, voluntary and independent sectors. It includes, for example, primary care teams, site-specific cancer teams, therapy teams and specialist palliative care teams, and reflects the practice of multidisciplinary/multi-sectoral team working.

I47 The Guidance is based on a view that patients and carers should be involved as equal partners with professionals in the provision of care. Emphasis is therefore placed on their existing resources to meet their own needs. Patients and carers should be seen as taking joint responsibility with professionals for their treatment and care, drawing on their own experience.

## F. Implementation of recommendations

I48 Commissioners and providers will need to work together, through Cancer Networks, to implement the recommendations in this Guidance. Partnership (service-user) groups and Cancer Services Collaborative ‘Improvement Partnerships’ should be involved.

I49 Although the Guidance concerns supportive and palliative care services commissioned and funded by the NHS, voluntary sector organisations have long made – and will continue to make – a considerable contribution. They play an important role in service planning and delivery at local and national level and might be commissioned to provide any of the services outlined.

I50 As many of the Guidance recommendations concern workforce development, close involvement of Workforce Development Confederations in England and the Workforce Development Steering Group in Wales will be needed to expand the workforce and to ensure access to high quality training. It is not, however, part of the remit of the Guidance to make specific recommendations on workforce issues.

- I51 The need to ensure systematic user involvement in cancer services has been recognised with the implementation of the Cancer Partnership Project in England, a joint Department of Health and Macmillan Cancer Relief initiative<sup>25</sup>. The Cancer Services Collaborative ‘Improvement Partnership’ Patient Experience project<sup>26</sup> is actively promoting patient and carer involvement in the change process. These, combined with the current Public and Patient Involvement Policy<sup>27</sup>, which established the Patient Advice and Liaison Service (PALS) and the Expert Patient Programme<sup>28</sup>, are creating a significant infrastructure to support the process.
- I52 In Wales, an all-Wales User Involvement initiative is funded by Macmillan Cancer Relief. Network structures have been established to incorporate user views. The Health Plan for Wales, *Improving Health in Wales*<sup>9</sup>, commits the NHS to enabling each citizen and community to play a role, directly or through representative bodies, in the development of health policy. It sets out measures to encourage patient and public involvement, including the development of Local Health Alliances, the *Communities First* programme aimed at encouraging participation among people from socio-economically deprived communities, and the establishment of a National Advisory Group to further develop public and patient involvement in Wales.
- I53 The Welsh Assembly Government, in partnership with the Office for Public Management, has also produced *Signposts*<sup>29</sup>, a guide to patient and public involvement (PPI) for those responsible for taking PPI forward within their organisations, and *Signposts Two*<sup>30</sup>, which focuses on tackling the challenges of developing PPI practice.
- I54 It is envisaged that the Guidance recommendations will be incorporated into the *Manual of Cancer Services Standards*<sup>31</sup> in England (and the all-Wales minimum standards for specialist palliative care<sup>18</sup>), and the quality of supportive and palliative care services will be monitored through the peer review process. This currently applies only to NHS secondary and tertiary care services. The Department of Health and Welsh Assembly Government will need to consider how best to extend this to primary care and to services provided by the independent sector for the NHS<sup>C</sup>. While the standards largely relate to structures and process, Cancer Networks need to develop mechanisms to monitor the outcomes of supportive and palliative care services.

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<sup>C</sup> Independent hospices in England have been inspected since April 2002 as part of the work of the National Care Standards Commission. These inspections include assessments of standards that were specifically developed for hospices and which draw on earlier drafts of this Guidance. From April 2004, this responsibility will transfer to the Commission for Healthcare Audit and Inspection (CHAI). The Care Standards Inspectorate for Wales, set up under the Welsh Assembly Government, carries out assessments of standards in hospices in Wales, based on national standards and other guidance on specific areas of care delivery.

## Priorities

- I55 The recommendations represent a set of priorities in areas most likely to make a difference to patients. Many may have already been implemented in some areas, and some incorporate recommendations generated by other sources, such as the Cancer Information Advisory Group in England.
- I56 It is not anticipated that all recommendations will be achieved in all areas immediately, or even in the short term. Some represent goals at which to aim. Strategic Health Authorities (SHAs), Welsh Assembly Regional Offices, Health Commission Wales, Primary Care Organisations, Local Health Boards, NHS Trusts, Cancer Networks and voluntary organisations will need to assess current service provision against the recommendations. From such an exercise, they will be able to identify areas of greatest deficiency in current provision and steps needed to provide solutions.
- I57 One basis for setting priorities might be the probable impact of implementing change, but this is likely to vary among geographical areas because of differences in existing services. The evidence suggests that change in some topic areas will have more impact for patients than others, although this may partly reflect the amount and quality of research in different areas.
- I58 Some recommendations include suggestions on how they might be addressed by commissioners and providers. In some cases, in the absence of research evidence, these are drawn from a combination of the clinical and service-user experience of members of the Editorial Board and other experts involved in the consultation process.
- I59 Local circumstances will dictate modifications in the way the Guidance is implemented. Cancer Networks should lead discussions among users and providers of services about the appropriate configuration of local services and the nature of care to be provided. Commissioners need to be fully engaged in this process, with primary care lead clinicians for cancer playing a key role.

## Ongoing research

- I60 Areas of uncertainty about the best models for supportive and palliative care services remain. In particular, research is needed on comparisons between different ways of providing services, including careful measurement of outcomes important to patients and carers. The final topic of the Guidance summarises the nature of current evidence in this area and outlines suggestions for future research with respect to interventions, populations, outcome measures and methods.

- 161 It is anticipated that the Guidance will help to set the research agenda for supportive and palliative care. Both the National Cancer Research Institute (NCRI) and the Wales Cancer Trials Network (WCTN) might act as vehicles through which relevant portfolios of studies can be developed. Evidence of the current state of research and suggestions for the design of future research have been submitted to the Supportive and Palliative Care Strategic Planning Group of the NCRI.

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# 1. Co-ordination of Care

## A. Introduction

1

- 1.1 People with cancer may require supportive and palliative care at different stages of the patient pathway and from a range of service providers in the community, hospitals, hospices, care homes and community hospitals. This means that services need to work closely together to ensure that patients' and carers' needs are addressed with no loss of continuity.
- 1.2 Health and social care professionals providing day-to-day care to patients and carers must be at the core of these services, and should be able to:
  - assess care and support needs, including needs for palliative care, of each patient and carer at all stages of the patient pathway and in all domains of care
  - meet those needs within the limits of their knowledge, skills and competence
  - know when to seek advice from or refer to specialist services
  - understand how to enable patients and carers to use their own knowledge and skills effectively.
- 1.3 *A Policy Framework for Commissioning Cancer Services* (the Calman-Hine Report)<sup>1</sup> emphasised the need for care to be seamless from the patient's perspective. Ensuring a smooth progression of care is a challenge, requiring:
  - excellent information transfer following the patient
  - effective communication between services and with patients and carers
  - flexible responses to changes in need over time
  - as few professionals as possible involved in the delivery of care, consistent with need.

- 1.4 The report of the Commission for Health Improvement/Audit Commission<sup>2</sup> identified numerous deficiencies in co-ordination of care for people with cancer. Unnecessary duplication of services was found to lead to confusion and waste of scarce resources. Patients suffered delays in obtaining needed services because of poor communication between sectors (such as secondary and primary care) on their conditions and treatments.
- 1.5 Inadequate assessment of patients' physical and emotional needs means that needs for supportive and palliative care are not recognised, resulting in services being denied to patients. Effective assessment hinges on the provision of appropriate education and training for health and social care professionals, feasible and sensitive assessment tools and the availability of skilled personnel.
- 1.6 Assuring that care is well co-ordinated at strategic and operational levels will lead to improved quality of life for patients and higher satisfaction with services. Where such co-ordination is absent, patients and their families may miss out on services, due to:
  - a failure to recognise patients' needs
  - a failure to access existing services, due to lack of familiarity with them
  - a failure of accessed services to meet patient needs in full, due to inadequate communication
  - a lack of services due to limitations in planning, funding or workforce capacity.
- 1.7 Many of these issues are being addressed at national level through the establishment of a Supportive and Palliative Care Co-ordinating Group in England and the Cancer Services Co-ordinating Group in Wales.
- 1.8 *The NHS Cancer Plan*<sup>3</sup> for England stated that supportive care networks would be established alongside Cancer Networks. Since then, many local areas have developed groups tailored to meet local needs, working closely with Cancer Networks. Regardless of the organisational structure at local level, everyone involved in providing cancer services should seek to ensure that care is of the highest possible quality and is well co-ordinated from patients' perspectives.



- 1.9 The Cancer Network is the vehicle for taking forward the implementation of the *NHS Cancer Plan*<sup>3</sup> in England and *Improving Health in Wales*<sup>4</sup> (see Box 1.1).

### Box 1.1 Cancer Networks

Cancer Networks are partnerships involving:

- Primary Care Organisations/Local Health Boards
- NHS Trusts
- hospices and other voluntary sector organisations
- councils with social services responsibilities
- health and social care professionals
- patients and carers.

Cancer Networks work in close partnership with Strategic Health Authorities (SHAs) and Health Commission Wales and their associated Workforce Development Confederations (the Workforce Development Steering Group in Wales).

- 1.10 Caring for patients with cancer currently comprises a very large part of the workload of those providing supportive and palliative care. The Guidance is therefore predicated on an assumption that supportive and palliative care will be organised within Cancer Networks.

## B. Objectives

- 1.11 The objectives are to ensure that:

- services are available to all patients who need them, when they need them
- care delivered by providers in different locations is well-co-ordinated from the perspective of patients and carers
- services are of the highest possible quality and are sensitive to people's needs.

## C. Recommendations

### C.1 Service provision and planning: specific recommendations

1.12 SHAs and Local Health Boards, working through Cancer Networks, should ensure that structures and processes are in place to plan and review local supportive and palliative care services. All relevant stakeholders in the provision and commissioning of such services (health, social care and voluntary) should be included. This will involve:

- assessing local need
- assessing existing service provision
- making recommendations on appropriate service configuration and development priorities to the Cancer Network Board, in order to contribute to the service delivery plan
- overseeing the development of Cancer Network-wide policies, guidelines and directories
- working closely with Workforce Development Confederations in England (and the Workforce Development Steering Group in Wales) on training and workforce needs
- developing joint operational policies and care pathways in partnership with local authorities and the voluntary and statutory sectors
- establishing Cancer Network-wide arrangements to ensure that health and social care professionals have access to up-to-date clinical information about patients and carers
- ensuring the views of patients and carers are taken into account from an early stage
- developing strategies that identify the needs of local people who have difficulty accessing services.

1.13 As much supportive and palliative care is provided by the voluntary sector, mechanisms should be established to support effective partnerships for service planning and provision. Local Compacts between the statutory and voluntary sectors should guide these partnerships. NHS bodies should have signed up to local Compacts by the end of March 2004.

- 1.14 The development agenda for supportive and palliative care is large and diverse. Cancer Networks should nominate an individual (or individuals) at Cancer Network-level to lead on supportive and palliative care, reporting to the Cancer Network Board.
- 1.15 Provider organisations should nominate one or more individuals to lead the development of supportive and palliative care services within the organisation and to contribute to the development of the Cancer Network-wide strategy.

## **C.2 Assessment: specific recommendations**

- 1.16 Assessment of patients' individual needs is a critical first step in ensuring they receive the services they require. Patients should be offered support to help them to assess their own needs so that the process becomes one of partnership between patients and professionals. At national level, it is recommended that work be undertaken to inform the process of developing assessment approaches/tools for use in routine practice by a range of health and social care professionals.
- 1.17 Patients should not be subjected to unnecessary repeated assessments from different professionals aiming to elicit similar information. To avoid such problems, providers and teams, working through Cancer Networks, should develop common approaches to assessment, including the use of specific assessment tools linked with other domains such as continuing, social and intermediate care.
- 1.18 Assessments should encompass all aspects of supportive and palliative care (see I9 and I13), including the preferences of patients and carers with respect to:
  - written and other forms of information
  - face-to-face communication
  - involvement in decision making
  - control of physical symptoms
  - psychological support
  - social support
  - spiritual support
  - rehabilitation
  - complementary therapies

- self-management and peer support
- family and carer support
- bereavement support
- involvement in the design and delivery of services.

Central to the process should be asking patients how they are feeling and helping them to assess their own needs. Patients are often the most effective assessors of their needs.

- 1.19 Teams should ensure that a structured assessment is undertaken at key points in the patient pathway and is recorded, with mechanisms developed for sharing the data among the multidisciplinary team. There should be a locally agreed format in which findings can be recorded. Findings should be discussed at multidisciplinary team meetings.
- 1.20 While assessment should be an ongoing process throughout the course of a patient's illness, structured assessments should, as a minimum, be undertaken at each of the following key points:
  - around the time of diagnosis
  - commencement of treatment
  - completion of the primary treatment plan
  - disease recurrence
  - the point of recognition of incurability
  - the point at which dying is diagnosed
  - at any other time the patient requests it.
- 1.21 Following each assessment, potential interventions should be discussed with patients and carers and a mutually agreed action plan formulated.
- 1.22 Provider organisations should ensure that health and social care professionals they employ have received training in assessing patients' and carers' needs. These professionals have a responsibility to ensure they have received such training before undertaking assessments.

### **C.3 Referral and access: specific recommendations**

- 1.23 Prompt referral to services should be agreed with patients following assessment. Teams should develop referral guidelines for services they offer, in accordance with any relevant Cancer Network guidelines.
- 1.24 Cancer Networks should ensure that a service directory is available to health and social care professionals, patients and carers. It should include information about national and local supportive and palliative care services provided by the NHS, other statutory and voluntary organisations, professionally-led support groups, self-help and peer-to-peer support groups, and local and national telephone helplines. The directory should include information on accessing information services (see Topic 4), psychological support services (Topic 5), specialist palliative care services (Topic 9), complementary therapy services (Topic 11) and support for families and carers (Topic 12). It should be kept up-to-date and a full review conducted annually.
- 1.25 Teams should ensure that patients and carers are given information on who they can contact at any time of day or night to obtain advice, support or services. Written information should include details of who to contact locally if patients have particular questions about their treatment or care. These resources should be available in languages appropriate to the local community, with specific attention to issues affecting black and ethnic minority communities and people with sensory impairment or learning disabilities. Service providers may wish to consider the provision of a single, local, 24-hour, seven days a week telephone access-point for patients and carers.

### **C.4 Co-ordination within teams: specific recommendations**

- 1.26 To enhance co-ordination within teams (whether hospital, hospice or primary care based) in relation to supportive and palliative care, teams should:
- discuss the needs of individual patients at multidisciplinary meetings
  - record the outcomes of these discussions and communicate them to the patient and carer (with the patient's permission)
  - review the dynamic processes within the team and with other teams/services to maintain continuing effectiveness; external support may be required to facilitate this.

- 1.27 While taking full account of national guidelines, teams should develop their own policies/protocols on communication and other key aspects of supportive and palliative care. This might be facilitated by mapping supportive care pathways for different groups of patients to identify at which points members of the team are involved.
- 1.28 Teams (including primary care teams) should be able to identify patients currently under their care. An example of how this might be achieved is provided by the Gold Standards Framework<sup>5,6D</sup>, in which general practices are asked to maintain a supportive care register to record, plan and monitor care for patients needing supportive and palliative care<sup>E</sup>. The 2003 General Medical Services contract<sup>7</sup> includes disease-specific registers (including cancer) as a quality indicator.
- 1.29 Teams, whether hospital, hospice or primary care based, should develop mechanisms to promote clinical continuity for patients. There is good evidence that patients want someone they can contact about their care at any one time. There is less evidence on how this might best be achieved. Teams may wish to consider nominating (with the agreement of each patient) a person to act as 'key worker'; this person might be, for instance, a community nurse, allied health professional, nurse specialist or social worker, and the role might involve:
- orchestrating assessments to ensure patients' needs are elicited
  - ensuring care plans have been agreed with patients
  - ensuring findings from assessments and care plans are communicated to others involved in a patient's care
  - ensuring patients know who to contact when help or advice is needed, whether the 'key worker' or other appropriate personnel
  - managing transitions of care.

Different practitioners are likely to perform this function on behalf of individual patients over time. Changes in 'key worker' are likely to be warranted at key transition points; where this becomes necessary, the change should be negotiated with the

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<sup>D</sup> The implementation of which is supported by the Macmillan Gold Standards Framework Programme.

<sup>E</sup> The NHS Information Authority is carrying out work to support the development of practice-based registers in primary care for a range of patient groups, including those with cancer. See <http://www.nhs.uk/nhsia/datasets/pages/pbrs.asp>

patient and carer and a clear hand-over organised. Evaluation of different models of the 'key worker' concept is highly desirable.

- 1.30 Each team should identify an individual to act as an administrative contact for patients and professionals. In addition to serving as a common access point during normal working hours (09.00-17.00, Monday-Friday), the person might also organise multidisciplinary meetings and maintain records so that teams can readily identify patients under their care. Patients and those providing care should be given the person's name and contact information in writing, including telephone numbers.
- 1.31 Provider organisations should ensure that multidisciplinary teams have access to office space and administrative support to enable all team members to fulfil their functions effectively.

## **C.5 Co-ordination between teams: specific recommendations**

- 1.32 Patients move frequently between sectors (home, hospital and hospice), between teams (primary care, cancer and palliative care teams) and between NHS, local authority and voluntary agencies. Co-ordination among these teams and services should be proactive to enhance continuity of care.
- 1.33 Co-ordination can be achieved in a variety of ways and will depend on local circumstances. Each team should identify the other teams/services with which they interact most frequently and should develop plans to promote co-ordinated care. These plans might include:
- establishing joint clinics
  - undertaking joint ward rounds
  - participating in multidisciplinary meetings that include people from different sectors
  - tele-conferencing.
- 1.34 Mechanisms to achieve comprehensive and timely information transfer between teams/services about patient care and treatment plans should be in place. This might involve electronic transfer of information, hand-over forms or patient-held records and correspondence. These should be consistent with the *Information for Health* strategy of the NHS Information Authority<sup>8</sup> in England (*Informing Healthcare: transforming healthcare using information and IT*<sup>9</sup> in Wales). In line with the English Electronic Patient Record (EPR) national programme and the Welsh Single Integrated Electronic Record, the largely

paper-based system currently used will be transformed by the implementation of national IT programmes and associated integrated care records services<sup>F</sup>.

## **C.6 Quality: specific recommendations**

- 1.35 Wherever possible, care should be evidence based and delivered in accordance with guidelines, policies and care pathways agreed at Cancer Network level.
- 1.36 Relevant experts from different provider organisations should contribute to the development of policies for the individual domains of supportive care. These policies should be reviewed regularly.
- 1.37 Cancer Network-wide audits, based on agreed policies, should be undertaken and the results used to inform service development.
- 1.38 Cancer Networks should encourage research on supportive and palliative care. The establishment of the National Cancer Research Institute (NCRI), the National Cancer Research Network in England and the Wales Cancer Trials Network (WCTN) should support the development and conduct of high quality clinical studies.
- 1.39 Progress should be reviewed with patient and carer representatives and their views should be taken into account in the planning and operation of services. Regular and systematic arrangements should be developed within Cancer Networks for obtaining patient and carer views about their experience of using supportive and palliative care services.

## **C.7 Research and development: specific recommendations**

- 1.40 Empirical research is needed to map patients' motivations, expectations and experiences of care in a range of contexts, to identify different services and patterns of care received, and to identify ways to improve local service co-ordination.
- 1.41 Evaluative research is needed to test different strategies to facilitate co-ordination between hospital and home, and health and social care.

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<sup>F</sup> For more information on the Integrated Care Records System (ICRS), visit: [http://www.doh.gov.uk/ipu/whatnew/specs\\_12d.htm](http://www.doh.gov.uk/ipu/whatnew/specs_12d.htm)



## D. Evidence

- 1.42 There is no evidence to support the establishment of one particular structure or process to plan and review cancer services. Managed clinical networks are currently being developed, but no evaluation is yet complete; one current evaluation is centred on the London Cancer Networks<sup>10</sup>. Needs assessment has become an established method of determining needs, and data are available in palliative care<sup>11</sup>. There is a significant risk of gaps and duplication in provision in the absence of systems to link the activities of those providing supportive and palliative care<sup>2</sup> [C].

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### D.1 Assessment

- 1.43 Because the perceptions of patients, carers and health and social care professionals frequently differ, the process of assessment can help to produce a common understanding of needs. Studies have reported that the assessment of physical symptoms and psychosocial needs is often inadequate [B]. Patients' needs will change as they progress through different phases of the patient pathway; re-assessment at regular intervals is therefore essential. Systematic assessment is associated with reduced symptom distress over time [B].

### D.2 Communication, co-ordination and continuity

- 1.44 The need for effective communication, co-ordination and continuity of care grows with the involvement of increasing numbers and categories of practitioners and interventions. Observational work has described patients' and carers' perspectives of continuity and barriers and how this negatively influences the experience of care<sup>12</sup> [B].
- 1.45 Few studies have examined the impact of continuity of care, or lack of it, on the process and outcomes of care<sup>13</sup>. Most have originated from specialist centres aiming to improve and extend their care. By far the most comprehensive was a Norwegian randomised controlled trial of integrated care which fielded a dedicated team to provide quick home care nurse referral, shared records, good GP links and a dedicated hospital-based co-ordinating group. Large increases in contacts and patient satisfaction were generated [A].
- 1.46 There is evidence that introducing a greater degree of co-ordination to existing services through organisational interventions such as hospital-based nurse specialists and community-based nurse co-ordinators leads to positive outcomes [A]. Professionals and patients often feel there is inherent value in initiatives designed to improve the experience of care, such as the notion of the 'key worker', a professional to whom patients and their carers can turn in the first instance for information and advice<sup>6,14,15</sup> [C].

- 1.47 Guidelines to maintain interactions between services and the establishment of multidisciplinary care plans have been shown to be worthwhile [A]. Many of these innovations have been evaluated only within the context of palliative care, but it is likely that enhanced co-ordination would result if similar interventions were also applied at other stages of the patient pathway. These need to be evaluated. In addition, many specialist palliative care teams include co-ordination as part of their role, and there is good evidence that this is effective [A] (see evidence review in Topic 9, *Specialist Palliative Care*).
- 1.48 Professional communication across organisational boundaries is a problem; the Cancer Services Collaborative has developed a 'Fax Pack'<sup>16</sup> setting out six triggers for fax communication between primary and secondary care services, ranging from an initial referral, through the diagnosis and start of treatment, to communication of a death. It includes a 'safe haven' policy, a process by which confidential information can be received and despatched securely in line with Caldicott Guardian recommendations [C].
- 1.49 Evidence of the impact of patient records designed to transfer information as patients move between home, hospital and primary care is equivocal. Some small-scale studies have suggested that the development of an acceptable patient-held record is often welcomed by patients, but is not without difficulty [B].
- 1.50 More than 20 teams within the Cancer Services Collaborative have been developing patient-held record systems of various kinds. A chemotherapy 'handbook' developed by the Northern Cancer Network, involving information and records, was almost universally appreciated by those responding to an evaluation questionnaire [B]. The Collaborative has also developed a template for patient-held records, providing suggestions for core components with an accompanying toolkit on some practical issues; patients and carers were consulted on the items to be covered<sup>17</sup> [C].
- 1.51 A recent large-scale, UK-based study designed to evaluate prospectively the introduction of a patient-held record for managing patients with advanced cancer provided no evidence on which to base their widespread promotion [A]. While patients and carers generally appreciated the record, there were disappointing levels of communication among professionals. The study team noted that local projects with committed clinicians and patients may prove popular and effective.

- 1.52 Further examples of tools used to improve communication and co-ordination within and between teams include multidisciplinary meetings, case conferences, unified assessment tools and hand-over forms. The value of these tools remains unsubstantiated. While there is consensus about the value of the concept of the 'key worker' role, the effectiveness of new key worker models needs to be evaluated as evidence emerges.

## E. Resource implications

1

- 1.53 Resources will be required for Networks to employ an individual to lead the development of supportive and palliative care services, at an estimated cost of between £0.6 - £1.2m for England and Wales as a whole.
- 1.54 The provision of Cancer Network service directories is estimated to cost up to £1m in the first year, assuming that all Cancer Networks would need to set up a new directory from scratch. Ongoing maintenance is estimated to be around £0.4m per annum in subsequent years.

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## 2. User Involvement in Planning, Delivering and Evaluating Services

### 2

### A. Introduction

- 2.1 People whose lives are affected by cancer can be viewed as experts on living with its consequences. Drawing on their experience, they can make a significant contribution to the planning, delivery and evaluation of services and, in some areas, have already done so. The term ‘user involvement’ is often employed to cover such activities by patients and carers.
- 2.2 An important distinction needs to be drawn between user involvement in decision-making about a person’s *own* treatment or care and participation in the development of services for *all* patients. The first is a theme that pervades all topic areas in this Guidance. This topic, however, focuses on the latter.
- 2.3 User involvement means enabling people who use – or may use – services to voice their experiences and influence broader care. They may participate in:
- service planning to ensure that services meet the needs of patients and carers
  - the evaluation of services
  - mutual support with other patients and carers through self-help and support groups and individual peer-to-peer support schemes.
- 2.4 User involvement may be direct or indirect. Direct involvement occurs where users are personally involved in decision-making through, for example, representation on committees or panels. The appropriate method will depend on the purpose of the exercise, the resources available and the preferences of the users involved. Indirect involvement occurs when health professionals gather information about user views and take these into account when making decisions. Such information may be collected by a variety of methods, including interviews, focus groups and discussions with existing user groups.

- 2.5 There is a role for user involvement in the planning of broad policies and in delivering specific practice. Service users need to be heard at local, regional and national levels and in a range of care settings, including the community, acute hospitals and hospices. All such involvement should reflect the diversity of those whose lives are affected by cancer, with views elicited from a variety of groups<sup>1</sup>.
- 2.6 Not all patients and carers will wish to be involved in service planning or other activities; nor are all patients in a position to be involved. Some patients, including those who are very ill, people who feel socially excluded and those whose preferred language is not English or Welsh, can face significant barriers in having their views heard<sup>2</sup>. Some users may feel ill-equipped to engage effectively with professionals. Professionals may also lack the confidence and skills necessary to work effectively in this area.
- 2.7 Involving service users in the evaluation of services is fundamental to ensuring patient-centred provision. This can occur in different ways and throughout the evaluation process, including setting the agenda, undertaking evaluation activities, and interpreting and disseminating results. Service providers commonly lack knowledge and expertise in the methods for undertaking such evaluations of patients' experiences. Service users often complain that they do not hear the outcomes of exercises or any action taken as a result.
- 2.8 Patients frequently express a need to receive support from others who are in similar circumstances<sup>3</sup>. Patient and carer self-help and support groups are an invaluable resource for providing such support within local communities. They range from independent groups run by patients or carers to professionally led groups set up by provider organisations. Some support groups have paid staff. Support groups can experience a range of practical difficulties, including finding suitable accommodation for meetings, publicising their existence to potential new members and communicating effectively with local professionals<sup>4</sup>. Relevant staff are not always aware of their existence or do not think to pass on their details to new patients and carers. In many areas, there are inadequate arrangements to ensure that people are able to contact local support groups<sup>5</sup>.
- 2.9 People newly diagnosed with cancer often welcome the opportunity to talk to someone with long experience of the condition on a one-to-one basis and see this as a valuable source of emotional support. Many patients with cancer are happy to take on this role, but can feel inadequately prepared to do so.

## B. Objectives

2.10 The objectives are to ensure that:

- user involvement is valued as an integral aspect of service planning and delivery
- the views of patients and carers are obtained, taken into account and acted upon by those developing and evaluating cancer services
- patient and carer led activity is recognised and supported as an integral part of cancer care.

2

## C. Recommendations

### C.1 Overview

2.11 Mechanisms should be established to enable the views of people with cancer and their carers to influence the development, delivery and evaluation of cancer services.

2.12 Regular opportunities should be provided for service users to put forward their views on the adequacy of cancer services, with feedback about how findings have subsequently been addressed.

2.13 Patients and professionals involved in user involvement activities should have an opportunity to develop their knowledge and skills to foster their confidence and underpin effective working relationships.

2.14 Patients with cancer and their carers should be given information about relevant local and national self-help and support groups.

2.15 Patient support groups and peer-to-peer support arrangements should be supported.

### C.2 Service configuration and delivery: specific recommendations

2.16 Cancer Networks should establish and support Partnership Groups involving patients, carers and local health and social care professionals. They should take their views into account when planning services.

2.17 Partnership Groups should develop arrangements to ensure they are able to draw on a wide range of views when involved in planning and evaluation activity; this should include direct representation of black and ethnic minority groups, those who have difficulty accessing services, and advocacy services.



- 2.18 Partnership Groups should engage with other bodies established to support public and patient involvement such as Patient Advice and Liaison Services and Patient Forums and, in Wales, Community Health Councils, ensuring that their activities are synergistic and complementary.
- 2.19 Partnership Groups should establish effective relationships with local self-help and support groups to ensure they are familiar with existing provision in this area. They might wish to develop locally agreed guidelines to inform the working practices of these groups, consistent with Cancerlink's good practice guide<sup>6</sup>.
- 2.20 Cancer Networks should ensure that information about local self-help and support groups, user groups and advocacy services is included in local service directories.
- 2.21 Provider organisations should nominate an individual to lead on developing and sustaining user involvement. This person should liaise with all clinical teams and services related to cancer to ensure patients' views are being elicited, collated and addressed.
- 2.22 Provider organisations should develop mechanisms to ensure the views of patients with cancer and their carers are elicited and taken into account. The choice of method(s) will depend on the purpose of the exercise, available resources and expertise, and the preferences of users involved. Outcomes should be fed back to patients and carers, staff, management and the public (where appropriate). This should include information about changes resulting from the process and explanations on why some issues cannot be addressed.
- 2.23 All multidisciplinary teams and services should have mechanisms in place to gather the views of patients and carers on a regular basis.
- 2.24 Provider organisations should work with local self-help and support groups to establish the most effective ways of supporting their activities. This might involve the provision of accommodation for meetings or offering training and support for support group leaders, co-ordinators or staff.
- 2.25 Teams should establish a process to ensure that all patients newly diagnosed with cancer and their carers are offered prompt details of local self-help and support groups using, for example, local service directories.
- 2.26 Teams should develop mechanisms to enhance patient access to peer-to-peer support. These should recognise the cultural sensitivities of patients, so that support is offered by people from the same cultural or ethnic group whenever possible.



### **C.3 Workforce development: specific recommendations**

- 2.27 Cancer Networks should ensure that user and professional members of Partnership Groups have access to training and support. Patients and carers may need training in confidence building, representation and committee skills and information on the organisation and management of the NHS. Users and professionals might be trained together, where they are working as part of a group.
- 2.28 Provider organisations should ensure that health and social care professionals have access to education in the principles and importance of user involvement and how to act on user views.

### **C.4 Research and development: specific recommendations**

- 2.29 Exploratory research is needed to determine the effectiveness of specific strategies for user involvement and to learn about the experience of users.
- 2.30 Research is needed to determine the most effective mechanisms for achieving user participation in the delivery of supportive and palliative care in different circumstances.

## **D. Evidence**

- 2.31 A number of studies have elicited the views of patients with cancer and their carers, nationally and locally, using different methods<sup>7-9</sup> [B]. Some have been used directly to influence service decisions<sup>10</sup> [B]. Successful methods of involving service users in planning, developing and evaluating services have been developed by a range of health care organisations<sup>11,12</sup> [C].
- 2.32 There is, however, a paucity of research which documents the impact of user involvement in health care. This may be partly due to the difficulty of tracing impact: policy issues can change rapidly, and it is not easy to attribute decisions to a particular source.
- 2.33 Two systematic reviews suggest that patient involvement in planning can result in some changes in service provision across a range of settings [A]. Such changes tend to concern patient information or access to services, but can also include the provision of new services. In addition, patient involvement can lead to a change in organisational culture. These findings are confirmed by a study of user consultation within Primary Care Organisations and NHS Trusts which notes that arrangements for such involvement are becoming increasingly common and have some impact, albeit fairly limited<sup>13</sup> [B].

- 2.34 Some research attention has been given to the training needs of patients likely to become involved in health policy or planning. Lay people would welcome joint training with professionals as a means of increasing collaboration [B]. Training should consist of communication skills training, representation skills and information on the NHS and voluntary sector. An evaluation of an advocacy training programme for patients with breast cancer found that participants became increasingly involved in boards and committees, clinical trial recruitment issues, patient resources and breast cancer advocacy groups, but not in every form of advocacy activity [B].
- 2.35 A number of studies have looked at patient support groups. An exploratory study evaluated the role of cancer support groups in the UK and identified strategies to improve communication with hospital staff [B]. Local support groups were found to be a considerable resource for patients with cancer, offering mutual support with a range of services not provided elsewhere. Hospital staff were not well informed about such groups, however, and were reluctant to refer patients to them. Another small study explored the activities of an advocacy project for patients with cancer, finding high attendance at meetings and positive feedback from participants [B].
- 2.36 From the limited research available, it is clear that patient involvement in decisions about health care can bring about changes in the provision of services, and partnerships between patients and professionals offer significant opportunities to improve health care. In addition, patient involvement can change the culture of organisations, making them more responsive to patients' perspectives. There is a need to enhance capacity through training and development for patients and practitioners and developing the contribution of patients' organisations<sup>14</sup> [C].

## E. Resource implications

- 2.37 A range of support, including payment of user expenses such as travel and child care, payment for users' time in selected activities including membership of professional committees, and training for and support of Partnership Groups, is estimated to cost around £1.7m per annum nationally.
- 2.38 Additional resources may be required for supporting the activity of self-help and support groups. It is recommended that commissioners give consideration to possible frameworks for supporting this type of activity within their local area.

- 2.39 Education and training for health and social care professionals in the importance, general principles and methods of user involvement will be required.

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## 3. Face-to-Face Communication

### A. Introduction

- 3.1 Interpersonal communication is the process through which patients and carers are helped to explore issues and arrive at decisions in discussions with health and social care professionals. It is most effective where there is mutual understanding, respect and awareness of individuals' roles and functions.
- 3.2 Patients and carers highly value face-to-face communication with skilled health and social care professionals who are able to 'engage with patients on an emotional level, to listen, to assess how much information a patient wants to know, and to convey information with clarity and sympathy'<sup>1</sup>. It is the usual mode of information-giving at critical points in the patient pathway, accompanied by opportunities for reflection and questioning and supplemented by written or other materials and telephone communications. There is a close relationship between good communication and the provision of emotional support.
- 3.3 Good communication is a prerequisite for enabling patients and carers to make informed decisions about care. Communication in which patients are encouraged to participate and to direct the flow of the communication is likely to result in improved patient outcomes. It can bring not only greater understanding, but also a heightened ability to participate in the decision-making process, better health-related quality of life and a better experience of care.
- 3.4 Good communication skills are therefore key to the delivery of effective supportive and palliative care services, but patients and carers frequently report that the communication skills of health and social care professionals are poor. Some professionals tend to make assumptions about the level of information required, rather than asking patients what they want to know.
- 3.5 Professionals may feel inadequately trained in some aspects of communication, such as sensitive listening, communicating significant news, explaining complex treatment options, exploring uncertainty (particularly in relation to prognosis) and discussing end-of-life issues. They may lack skills in eliciting

patients' needs for information and their desire for involvement in decision making. They may also lack the necessary skills to be able to communicate effectively with people with hearing, sight, speech or combined sensory disabilities, those with learning disabilities, people whose preferred language is not English or Welsh, and those from minority ethnic backgrounds and traditions. There may also be problems in communicating with the children or grandchildren of people with cancer.

## B. Objectives

3.6 The objectives are to ensure that:

- patients and carers are able throughout the patient pathway to discuss problems concerning the disease, treatments and impact with professionals who are knowledgeable and skilled communicators
- health and social care professionals listen and respond to patients and carers in a manner that enables decisions to be made in an atmosphere of genuine partnership
- patients are given the opportunity to participate in decision making about their treatment and care.

3

## C. Recommendations

### C.1 Overview

- 3.7 Patients' preferences on involvement in making decisions about their own care should be assessed on an ongoing basis.
- 3.8 Health and social care professionals should have the skills to communicate effectively with patients and carers. Those who must communicate particularly complex or distressing information should have enhanced skills or be supported by someone who has those skills.
- 3.9 Any significant news, such as a diagnosis, should be communicated honestly to a patient with the minimum of delay.
- 3.10 The outcome of significant consultations should be recorded in the patient's notes, with the patient being offered a permanent record of important points. Patients should be offered the opportunity to review discussions at key consultations at a later date.
- 3.11 Suitably trained and skilled interpreters and advocates should be available for patients whose preferred language is not English or Welsh and who want them.

- 3.12 Accredited training courses in communication skills should be available for all health and social care professionals who work with patients and carers.

## **C.2 Service configuration and delivery: specific recommendations**

- 3.13 Teams should ensure that patients' and carers' involvement in decision making about their own care is facilitated where desired. This should include eliciting patients' own knowledge about their condition, treatment and care. People are likely to vary in the extent to which they want to be involved and in the particular decisions in which they wish to have a say. Preferences may also change over time, and should therefore be assessed on an ongoing basis. Choices on involvement should be recorded and shared with all those involved in care of the patient and carers.
- 3.14 Health and social care professionals should ensure they understand the cultural dimensions of face-to-face communication and cultural sensitivities relating to cancer and its treatment. They should aim to respect individuals' cultural values and traditions when engaging in face-to-face communication.
- 3.15 All health and social care professionals should be able to judge whether they have addressed an individual's communication needs; where there is a clear need for a more experienced person, this should be arranged without delay. Requests from patients to see a more experienced professional should be accepted gracefully.
- 3.16 Provider organisations should ensure that patients and carers have access to professionals with appropriate communication skills. Patients should have the opportunity to discuss problems, concerns and treatment options with a member of staff who has expertise in the relevant area and is an effective communicator. They should be able to discuss matters further with a professional of their choice.
- 3.17 A diagnosis should be communicated honestly to a patient with the minimum of delay. This information should be given in a comfortable, quiet area, with privacy and without interruption, ideally in the company of a close relative or friend (if the patient so wishes) and in the presence of a specialist nurse where possible. Multidisciplinary teams might follow the guidelines outlined in the report *Breaking Bad News*<sup>2</sup>.
- 3.18 Teams should ensure that the communication of significant news is normally undertaken by a senior and competent clinician. In addition to having expertise in the disease and treatment options, he or she should have received advanced communication skills

training and been assessed as being an effective communicator. This may not always be practical, however, as patients and carers often ask less experienced staff searching questions about their condition and care. Provider organisations should therefore ensure that all staff are able to respond appropriately in the first instance before referring to a senior colleague.

- 3.19 Teams should ensure that the outcome of consultations in which key information is discussed should be recorded in the patient's notes with the patient being offered a permanent record of important points. The outcome of the consultation should be communicated swiftly to other health and social care professionals involved in the patient's care.
- 3.20 At the close of a key consultation, the patient should be offered an opportunity to explore issues and ask further questions. This can be done in a number of ways: a nurse specialist might remain behind to provide support and further information, a second appointment might be offered, or patients might be reminded about the contact details of their 'key worker' (see Topic 1, *Co-ordination of Care*). Teams should develop mechanisms to enable patients to review discussions from key consultations at a later date, should they so wish.
- 3.21 Provider organisations should ensure that for consultations where key information is discussed and important choices made involving individuals whose preferred language is not English or Welsh, or where patients have made a specific request, professional health care interpreters or advocates are always present<sup>G</sup>.
- 3.22 Services should not rely heavily on family members as interpreters, and should only seek their participation in extraordinary circumstances. Where the patient wishes and the person is willing, however, family members might be used as interpreters on occasion, particularly for day-to-day encounters.
- 3.23 It is not recommended that children be asked to provide interpreting services for parents or other members of their family.
- 3.24 Provider organisations should ensure suitable services are available for people with hearing, sight, speech or combined sensory disabilities and for people with learning disabilities to enable them to participate fully in information exchange. Provider organisations should ensure health and social care professionals are aware of these services and know how to access them.

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<sup>G</sup> *The NHS Plan* committed to having a national translation and interpretation (T&I) service under the auspices of NHS Direct. NHS Direct has been charged with procuring a national T&I service provider that will enable them and the wider NHS to access a quality assured service at a negotiated rate. More information will be made available during 2004/2005.



### **C.3 Workforce development: specific recommendations**

- 3.25 It is essential that staff have the necessary communication skills to underpin and develop quality services. Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should ensure that accredited training courses in communication skills are available for all health and social care professionals who work with patients and carers. A pilot scheme is currently under way in England under the auspices of the Department of Health and the NHSU, examining the feasibility of a cascade model of communication skills training. This involves training communication skills facilitators at Cancer Network-level to deliver courses to an agreed curriculum to senior practitioners.
- 3.26 Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should also ensure that health and social care professionals undergo diversity or cultural awareness training to promote effective communication with people from ethnic minority communities.
- 3.27 Cancer Networks, in association with Workforce Development Confederations in England (the Workforce Development Steering Group in Wales), should decide which staff groups should be given highest priority for advanced training. For example, they may want to ensure that, as a first priority, advanced skills training courses are available for senior personnel (such as consultants, specialist registrars, nurse specialists and GPs) who frequently have to break significant news, explain complex treatment options or discuss end-of-life issues.
- 3.28 Provider organisations should develop mechanisms to identify individual staff who may benefit from communication skills training, and a system should be established to evaluate how effectively they communicate. This might involve a process of performance appraisal, which should include the views of patients and carers. Arrangements should be in place to manage those staff members who repeatedly demonstrate poor communication skills.
- 3.29 Staff should undergo regular evaluation and updating of communication skills and should be able to access clinical supervision or other effective means of ongoing support.

### **C.4 Research and development: specific recommendation**

- 3.30 Evaluative research is needed to determine the best ways of ensuring that professionals trained in communication skills maintain their skills over time, particularly in emotionally charged situations.



## D. Evidence

### D.1 Communication skills training

- 3.31 There is growing evidence to support the development of effective models through which to deliver training for specific groups [A]. As this is a relatively new area, only one systematic review has been published on communication, and a further systematic review has been published through the Cochrane Collaboration Effective Practice and Organisation of Care (EPOC) Group<sup>3</sup>.
- 3.32 Training in communication skills can change health care professionals' attitudes, improve methods of eliciting concerns and offering information, and increase their confidence in dealing with communication challenges such as informing patients about their diagnosis and prognosis.
- 3.33 Intensive communication skills training programmes have been demonstrated to improve senior doctors' communication behaviour [A]. Other studies support the positive effects of education courses in improving health care professionals' communication skills, with ongoing training being necessary to maintain skills [A].
- 3.34 Evaluated training programmes have varied in content and design, but those that lead to positive outcomes tend to:
- include cognitive, behavioural and emotional aspects of communication and focus on the acquisition of skills and/or strategies for dealing with specific situations
  - use a combination of didactic and experiential methods, including role play, group work and discussion
  - be learner-centred
  - provide a safe environment for the development of skills, reflection and self-awareness
  - have defined and measurable core competencies
  - be led by professionals who are trained and understand issues relevant to the clinical context
  - provide constructive feedback.
- 3.35 Improvements are most likely to be maintained where courses involve a large component of experiential learning over an extended period [B]. Most training has involved a single-profession approach, but the benefits of training health care professionals together are increasingly acknowledged [A].

## D.2 Communication process

3.36 There is considerable evidence of problems in the communication between health care professionals and patients and carers. Diverse methods to improve the face-to-face communication process and support patient involvement in decision making (where patients wish) have been evaluated. Attempts to improve communication through different media can have positive effects on a variety of patient outcomes such as satisfaction, recall of information, self care, symptom management and psychological distress. The following approaches have been found to be beneficial.

- A written or taped record of the consultation [A]. Such records can help patients by improving their recall and giving them the opportunity to consider information after a consultation. They can also facilitate discussion with friends and relatives. Although most patients find them helpful, they can increase distress in those who want minimal information and in those for whom the prognosis is poor. A number of teams within the Cancer Services Collaborative have initiated taped consultations and written summaries of consultations. In Leicester, two-thirds of patients with lung cancer and lymphoma took up an offer of tapes of their consultation and, of those who responded to a survey (about 51%), all found them useful. They commonly listened to their tape on several occasions and felt that it provided much useful information and clarification [B]. In Wirral, four-fifths of the patients in one consultant surgeon's outpatient clinic took up an offer to receive copies of correspondence to their GP. This required some additional time in explanations to patients and paperwork, but was considered to work well [C].
- Individualised education sessions with a patient or carer, usually provided by nurses [A].
- Supporting patient involvement in treatment decision-making through the use of decision aids [A]. While a systematic review<sup>4</sup> acknowledges that evidence about the likely effects in people with cancer is limited, decision aids may offer a useful way of displaying and providing information about treatment and care options. Individual preferences for different levels of involvement in decisions must be respected.
- Pre-consultation training in the waiting room [B], found to be beneficial for patient participation in decision making and as preparation for significant consultations.

- 3.37 To date, no published research evidence on professional interpretation services has been found. Current consensus is drawn from patient and clinical experience [C].

## E. Resource implications

- 3.38 Provision of permanent records of important points of consultations is estimated to cost around £2.9m per annum, assuming a 75% uptake and a mix of methods used - taped consultations, provision of an individualised written summary of the consultation, or provision of a copy of the letter to the referring doctor/GP.
- 3.39 The cost of providing interpreters for patients who cannot understand or speak English is estimated at £0.7m for England and Wales, although there is likely to be significant variation between Cancer Networks.
- 3.40 Provision of communications skills training will have major resource implications. The total annual cost of training will be dependent on the number of places offered per year by Cancer Networks. Given an estimated cost per patient of £722 for training of senior staff (based on a three-day residential course), these costs will be significant. Cancer Networks will need to work closely with Workforce Development Confederations in England and the Workforce Development Steering Group in Wales to identify, prioritise and cost training and education requirements.

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## 4. Information

### A. Introduction

- 4.1 Most patients and carers want information about cancer and its treatment throughout the patient pathway. They expect information to be up-to-date and of high quality (see Box 4.1). The nature, level and format of information sought may vary, depending on many factors, including the stage of the disease and cultural and ethnic influences.

#### Box 4.1 High-quality information

Information needs to be of high quality to inform, support and reassure patients and carers. This means it must meet the needs of the target group and be evidence-based, balanced, regularly updated, culturally sensitive, available in a variety of formats and composed in plain language. Service users and experts must be involved in its design and development.

The Coalition for Cancer Information is currently piloting a process to accredit organisations that develop information materials.

- 4.2 Information can come in a variety of forms. The most obvious are patient leaflets, but audio and videocassettes, Internet websites, CD-ROMs and DVDs can also prove helpful. Some patients may wish to read more extensively - books by people with cancer about their feelings and experiences, for example.
- 4.3 Patients and carers cannot express preferences about their care or make choices on whether to be involved in decision making unless they are given appropriate information. Many report, however, that they receive insufficient information from health and social care professionals, and that the information they do receive is inadequate and of variable quality. There can also be a tendency for professionals to make assumptions about the amount or nature of information patients seek, rather than asking them directly.

- 4.4 Many different organisations at local and national level are involved in the production of information, leading to unnecessary duplication of effort, inconsistency in quality and failure to use evidence-based methods. Leaflets and other information materials are not always available where they are needed most, whether in a hospital, a primary health care centre or other locations in the community; they can also be out-of-date. Culturally sensitive materials in languages other than English are lacking, as are those suitable for children of patients, people with sensory deficits and people with learning disabilities. Although there is an enormous amount of information on the Internet, this is of variable quality and many patients lack the skills or resources to access it.
- 4.5 Providing information to people with cancer and carers should be an ongoing process, not a one-off activity. Patients and carers are reassured when they know that their information needs will continue to be met at each stage of the patient pathway.

## B. Objectives

- 4.6 The objectives are to ensure that:
- all patients and carers have access to high quality information materials when they need them, in a format and at a level of complexity appropriate to their needs
  - patients and carers are offered help to understand information materials, should they so request, to enable them to decide what care options are most appropriate for them
  - patients and carers have access to sources of emotional support to help them cope with the impact of information received.

## C. Recommendations

### C.1 Overview

- 4.7 A comprehensive range of high quality information materials should be available locally to patients in a variety of formats, free at the point of delivery. Access to further sources of information should be available, should patients request it.
- 4.8 Leads for cancer information should be appointed at Cancer Network, NHS Trust, service and team levels.

- 4.9 Decisions on local policy on information should be driven by the experiences of patients and carers, with the adequacy of local provision reviewed regularly in collaboration with groups of service users.
- 4.10 Patients' and carers' needs and preferences for information should be assessed on an ongoing basis and provision of materials tailored accordingly.
- 4.11 Patients and carers should be offered help to navigate the different sources of information available, assistance to understand the content of information materials, emotional support to cope with any difficult implications and advice on how to access and use information materials.
- 4.12 Information materials tailored to meet the needs of people from black and ethnic minority communities, people with sensory deficits and those with learning disabilities should be available.
- 4.13 Organisations that develop information materials for people with cancer should be subject to a national accreditation process.

## **C.2 Service configuration and delivery: specific recommendations**

- 4.14 A number of steps should be taken to ensure that high quality information is available and accessible to people with cancer and their carers when they need it. Information in all formats should be:
- developed
  - disseminated to the locations where patients and carers can access it
  - delivered free at the point of delivery to patients and carers.

In addition, information should be updated on a regular basis and out-of-date material destroyed.

## **Development**

- 4.15 The Department of Health and Welsh Assembly Government should oversee the commissioning, design, quality assurance<sup>H</sup> and compilation of a comprehensive range of high quality information materials for people affected by cancer, covering three different levels of information (Box 4.2). In England, the Coalition for Cancer Information, which brings together people

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<sup>H</sup> The Coalition for Cancer Information for England is taking forward work on quality assurance guidelines which will be reviewed following piloting.

from the statutory and voluntary sectors, will undertake this role. The Coalition should accredit organisations that develop information at national and local level according to specified criteria, and should ensure that commissioners of cancer services and other provider organisations are informed about such nationally accredited information material.

#### Box 4.2 Three levels of information

- Brief introductory information.
- General information on issues such as diet and cancer, radiotherapy and chemotherapy and information on specific types of cancer, types of treatment and aspects of living with cancer.
- Detailed and focused information, such as that presented in The Cancer Library available via The Cochrane Library.

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- 4.16 The Coalition for Cancer Information should lead the development of a national core set of accredited information materials, available in translation, for people from black and ethnic minority communities.

### Dissemination

- 4.17 Commissioners should ensure that comprehensive, high quality, nationally developed and accredited information materials are disseminated to all locations where people with cancer and their carers are likely to look for them, including GP surgeries, primary health care centres, hospitals and hospices. These materials should be free at the point of delivery. Materials should be made available, where possible, in a variety of formats to ensure they are accessible to as many people as possible. Electronic formats have the advantage that they can be updated more readily than printed versions.
- 4.18 Policies should be developed at local (Cancer Network/provider organisation) level detailing which information materials should routinely be offered at various stages in the patient pathway to patients with particular cancers. For example, new patients might be provided with a cancer information pack that contains timely, clear information in a convenient format. This information could be tailored to their personal needs, supplemented with generic information to help them to put their own experiences in context. Additional information materials should be available to meet individual requests. A representative of each multidisciplinary team should be involved in developing these policies.



- 4.19 Service users should play an integral part in the decision-making process not only about what information materials are made available, but also about how they are presented.

### **Delivery**

- 4.20 Provider organisations should ensure that patients and carers have easy access to a comprehensive range of high quality information materials including books, leaflets, audio and videocassettes, Internet websites, CD-ROMs and DVDs. These should be culturally sensitive for the local community and appropriate to different ages, backgrounds and stages of disease. The materials should be available in sufficient quantities to ensure that patients at all stages of the patient pathway are able to receive information. Materials should be archived, so that patients and staff can find the relevant materials efficiently. Within acute hospitals, this might be achieved through a dedicated cancer information centre, or through a facility that encompasses information for a broader range of diseases.
- 4.21 People with cancer request different styles of information, in different formats, and at different levels. Health and social care professionals must be prepared to help patients to navigate the different sources of information available and to meet requests for additional information. On the other hand, some patients and carers may not wish to obtain information. Preferences should be assessed on an ongoing basis; the extent to which information might be personalised or tailored for the individual concerned should be part of this process. Health and social care professionals may need to exercise caution in their assumptions about what information patients are ready to receive.
- 4.22 Teams should ensure that patients and carers are able to discuss information with a health or social care professional in a private environment, with support where needed to cope with its emotional impact. Patients' attention should also be drawn to other sources of assistance to understand and interpret information, such as helplines and support groups. Contact details should be provided in writing, if requested.
- 4.23 Provider organisations should ensure that patients and carers are offered advice and support on how to access and use information materials, including those located on the Internet. Service directories produced by Cancer Networks should contain a list of high quality websites, including NHS Direct Online, which plays a key role as a gateway to sources of accredited information.



- 4.24 Provider organisations should ensure that, where translations are not currently available, arrangements are in place to translate culturally sensitive information materials into a patient's preferred language. Organisations should purchase materials from a nationally accredited information provider, unless materials in the appropriate language are not available<sup>1</sup>.
- 4.25 Provider organisations should give special consideration to the best ways of providing access to information and support to people from black and ethnic minority groups. This may include training specific members of these communities on issues such as general awareness of cancer and where to access services, information and support.
- 4.26 Provider organisations should make arrangements to ensure the provision of suitable information resources for people with hearing, sight, speech or combined sensory disabilities and people with learning disabilities. There should also be information suitable for sharing with children and younger people.
- 4.27 Provider organisations should ensure that the adequacy of local information provision is reviewed regularly, in collaboration with groups of service users.

### **C.3 Workforce development: specific recommendations**

- 4.28 Teams should be familiar with their local patient information resources and should be able to provide relevant materials to patients if required.
- 4.29 Cancer Networks and NHS Trusts providing cancer services should nominate a lead for cancer information. The Cancer Network lead should oversee the development and implementation of effective information strategies for patients with different types of cancer being cared for in different locations. The Trust-level lead should ensure coherence across types of cancer. He or she should be responsible for ensuring that up-to-date materials are available and that patients actually receive them. This may be a full-time post in larger acute NHS Trusts.

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<sup>1</sup> A 'content bank' of core information on cancer is currently being produced. This will be available to be 'cut and pasted' from the NHS Direct Online website for anyone to use. Materials will be available in translation, and some work is currently being undertaken within NHS Direct to identify appropriate languages for specific materials. More information will be made available during 2004/2005.

- 4.30 Each specialist site-specific cancer team and each service (such as radiotherapy, chemotherapy, palliative care and primary care) should nominate an individual to take a lead on information to implement policy at local level. The holders of such posts might come from one of several professional backgrounds - a nurse specialist, community nurse, radiographer or pharmacist, for example; they should contribute to the development of Cancer Network-wide policies for their area.
- 4.31 Workforce Development Confederations (the Workforce Development Steering Group in Wales) should ensure that health care professionals receive appropriate training to enable them to provide information or to 'signpost' patients and carers appropriately.

#### **C.4 Research and development: specific recommendations**

- 4.32 Research is needed to determine cost-effective ways of exchanging information, such as decision aids and innovative technology, at different stages of care.
- 4.33 Research is needed to determine cost-effective ways to support patients in using information resources.

### **D. Evidence**

- 4.34 There is a substantial body of evidence on the information needs of people with cancer, the effectiveness of different ways of presenting information in a clinical setting, patient satisfaction with information-giving by health professionals, and the direct and indirect benefits of receiving information.
- 4.35 A systematic review has evaluated methods of giving information to patients with cancer and their carers [A], with strong evidence that patients and carers value – and benefit from – receiving accurate and relevant information. Outcomes of receiving full and clear information include improvements in knowledge and understanding, reductions in anxiety, increased preparedness for events, enhanced sense of control, enhanced compliance and increased satisfaction with treatment.
- 4.36 There is also support for information being provided in a variety of formats and at all stages of the patient pathway, mainly through studies conducted to establish the effectiveness of different methods of providing information. Such formats include:
- cancer information booklets, both general and specific [B]
  - individualised, structured nursing interventions to provide information and teach self-care and problem-solving skills [A]

- group information, discussion and support sessions [A]
- audiotapes, video tapes and slide tape programmes [A]
- interactive media such as computer assisted learning [B].

4.37 The timing of information provision appears to be important. Patients appreciate receiving information prior to first appointments [B]. They prefer to receive general cancer information at the treatment decision stage [B], and look for specific information before treatment [B].

4.38 The evidence further emphasises the importance of tailoring information to match patients' and carers' educational background, cultural needs, and general level of comprehension<sup>1</sup>. Patients also prefer information based on their own medical records, rather than general information [A].

4.39 Many Cancer Services Collaborative projects aimed at improving the experience of care are piloting different ways in which to tailor written information, although formal evaluation has been patchy [C]. Much of this activity involves local tumour-specific information, with attention to the expected treatment in a local hospital; the Royal Devon and Exeter NHS Trust, for instance, has developed a leaflet on its joint gynaecology/oncology clinic. Some teams have also developed tumour-specific information materials to be used across the Cancer Network; for example, a standardised information pack has been developed for patients with breast cancer in mid-Trent. Personal Information Files have been implemented in some clinical areas<sup>2</sup> [B], and recordings or summaries of consultations have also been provided (see Topic 3, *Face-to-Face Communication*).

4.40 The Cancer Services Collaborative has also offered patients 'key contact' cards with telephone numbers, setting out who they should contact when they have concerns or in an emergency (see, for instance, the system in operation in Avon, Somerset and Wiltshire Cancer Network) [B].

4.41 If the information needs of patients and carers are to be met, health and social care professionals are likely to need support<sup>1</sup>. The significant organisational challenges in producing, implementing and reviewing guidelines devoted to patient information, such as ensuring adequate funding, space and time, have been recognised, and the recommendations reflect those already in existence<sup>3</sup> [C]. Instruments are available to assess the quality of written information. Guidance has also been developed to assist in the production of and search for good quality information materials<sup>4-9</sup>.

- 4.42 Promoting access to information is a prime concern, and there are many locations where cancer information could be made available to patients and carers by a variety of different statutory and voluntary agencies. Hospital, community and mobile Cancer Information Centres, cancer telephone helplines and the National Electronic Library for Health have been developed. Evaluations indicate that patients and carers are highly satisfied with the quality and amount of information they receive from these types of information resources<sup>10,11</sup> [B], but the number of people contacting and using them suggests a need for provider organisations to promote increased access to existing sources of high-quality information materials.
- 4.43 The most effective ways of extending access to cancer information for people from black and ethnic minority communities are currently being explored through the National Opportunities Fund *Living With Cancer* projects<sup>J</sup>, and an evaluation is in process at City University, London.

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### E. Resource implications

- 4.44 Additional resources will be necessary for the provision of high-quality information and educational material for patients and carers. Total costs are estimated to be around £2.5m for providing all patients with a range of high-quality booklets.
- 4.45 The development of dedicated cancer information centres to ensure patients have easy access to a range of different materials is estimated to cost around £7.0m for England and Wales, including staff and equipment costs. Staff costs include an information lead for each Cancer Network, managers at the information centres and administrative support staff. Capital costs are excluded.
- 4.46 Training in information giving, including training of information centres managers and staff, will be needed.

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<sup>J</sup> A list of all funded projects under the National Opportunities Fund *Living With Cancer* initiative can be found at: <http://www.nof.org.uk/default.aspx?tc=22&tct=10>

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# 5. Psychological Support Services

## A. Introduction

- 5.1 Psychological distress is common among people affected by cancer and is an understandable and natural response to a traumatic and threatening situation. Patients at every stage of the patient pathway can find themselves dealing with difficult and distressing issues. They can develop problems ranging from sadness or worry to psychological symptoms sufficiently intense to interfere with their ability to function on a day-to-day basis.
- 5.2 People use a variety of resources to respond to this distress, including their own inner resources and emotional support from family and friends. For some patients, however, the level and nature of their distress is such that they would benefit from professional support.
- 5.3 Around the time of a diagnosis of cancer, approximately half of all patients experience levels of anxiety and depression severe enough to affect their quality of life adversely. About one quarter continue to be so affected during the following six months. Among those who experience recurrence of disease, the prevalence of anxiety and depression rises to 50% and remains at this level throughout the course of advanced illness. In the year following diagnosis, around one in ten patients will experience symptoms severe enough to warrant intervention by specialist psychological/psychiatric services. Such symptoms can also be seen in 10-15% of patients with advanced disease.
- 5.4 Patients and carers are likely to benefit from some form of professional psychological support whether they experience mild and transient emotional turmoil or severe depression (for particular issues affecting families and carers, see Topic 12, *Services for Families and Carers, including Bereavement Care*). The appropriate psychological intervention will depend on the nature and severity of the person's psychological problem, his or her previous psychological problems, the quality of social support available and the prognosis.

5.5 Psychological support services assess and help patients with psychological problems of all types and levels of severity, including:

- anxiety, including adjustment disorders, generalised anxiety states, phobias and panic attacks
- depression, ranging from adjustment disorders to severe clinical depression
- problems with personal relationships, including communication with health and social care professionals
- psychosexual difficulties (such as erectile dysfunction and loss of libido)
- alcohol and drug-related problems
- personality disorder
- deliberate self-harm
- psychotic illness
- organic brain syndromes.

5.6 A range of psychological interventions can be offered by both the statutory and voluntary sectors. Health and social care professionals offering day-to-day care provide much general psychological support to patients and carers and play a key role in psychological assessment and prevention and amelioration of distress. More specialised services include counselling, clinical and health psychology, liaison psychiatry and social work. These may be available as an integral part of local cancer services or may be part of generic mental health services, primary care services or hospice care. They can be located in GP practices, hospitals or hospices. The voluntary sector provides additional services, including telephone helplines and self-help and support groups.

5.7 Patients' psychological symptoms are often not recognised, with the result that they are not offered access to needed services<sup>1</sup>. Health and social care professionals often lack appropriate assessment skills and may underestimate the benefits of psychological support. Some do not know to whom they can turn for advice and support for patients and carers in distress.



- 5.8 There are insufficient numbers of professionals equipped to offer support to patients and carers in psychological distress, and no uniform agreement exists on the services that should be provided by relevant professional disciplines. There is also little co-ordination between professionals offering different types of psychological intervention, with the result that many people with cancer do not gain access to needed services of this kind.

## B. Objectives

- 5.9 The objectives are to ensure that:
- the psychological needs of all patients and carers are assessed on a regular basis throughout the patient pathway, with attention given to those points known to be particularly challenging, such as around the time of diagnosis, as treatment ends and at recurrence
  - patients and carers are offered psychological support appropriate to their needs, with those experiencing particular distress referred to professionals with specialist expertise
  - the psychological needs of staff caring for patients and carers facing difficult circumstances are adequately met.

## C. Recommendations

### C.1 Overview

- 5.10 The psychological well-being of patients and carers should be explicitly assessed at key points in the patient pathway.
- 5.11 All staff directly responsible for patient care should offer patients general emotional support based on skilled communication, effective provision of information, courtesy and respect.
- 5.12 Patients and carers found to have significant levels of psychological distress should be offered prompt referral to services able to provide specialist psychological care.
- 5.13 Emergency psychiatric services should be available when necessary. Patients with severe mental health problems may require these services in and out of normal working hours.





- 5.14 Psychological assessments and interventions should be undertaken in facilities that are quiet, comfortable and which confer privacy.
- 5.15 Staff providing psychological care should be adequately trained and supervised, and mechanisms to ensure support should be available.

## **C.2 Service configuration and delivery: specific recommendations**

- 5.16 Commissioners, working through Cancer Networks, should ensure that all patients undergo regular systematic psychological assessment at key points in the patient pathway and have access to an appropriate level of psychological intervention. A Cancer Network-wide approach to delivering psychological support, consisting of professionals competent to provide a variety of interventions whatever their organisational location, would facilitate this aim. Voluntary sector services should be integral to the network of service provision.
- 5.17 A four-level model of professional psychological assessment and intervention should be developed and implemented in each Cancer Network (Figure 5.1). Professional psychological support at Levels 1 and 2 should, in the first instance, be provided by health and social care professionals directly responsible for the care of people with cancer. More severe psychological distress (Levels 3 and 4) should be managed by a variety of psychological specialists, including counsellors, mental health nurses, clinical and health psychologists, psychotherapists and liaison psychiatrists. It may be necessary for such specialists to work across the Cancer Network, including in primary care, hospitals, hospices and the community, to achieve this model of care. It is also essential that health and social care professionals empower and equip patients to recognise and manage their own psychological needs.
- 5.18 GPs, oncologists and palliative care physicians also have an important role in the psychological care of patients and carers, which includes the prescription of antidepressant and other psychotropic medication.
- 5.19 This model should be underpinned by a recognition that patients and carers can often assess their own emotional status and meet their own needs for support. They might choose support from family, friends or self-help and support groups. Many develop a significant repertoire of self-management strategies.

**Figure 5.1**

<b>Recommended model of professional psychological assessment and support</b>				
	<b>Level</b>	<b>Group</b>	<b>Assessment</b>	<b>Intervention</b>
 <b>Self help and informal support</b> 	1	All health and social care professionals	Recognition of psychological needs	Effective information giving, compassionate communication and general psychological support
	2	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological techniques such as problem solving
	3	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework
	4	Mental health specialists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions such as psychotherapy, including cognitive behavioural therapy (CBT)

5.20 The model encompasses the range of psychological skills and expertise on which patients may draw and represents the diversity of psychological skills covered by different professional disciplines. The function of each level of provision is as follows.

### **Level 1**

5.21 Involves all staff directly responsible for patient care and is focused on general emotional care.

#### *Assessment*

5.22 All health and social care professionals should be able to recognise psychological distress and should be sufficiently competent to avoid causing psychological harm to patients and carers. They should know when they have reached the boundary of their competence and should refer the patient to a more specialist service.

5.23 Cancer Networks should develop criteria for referral to specialist psychological support services. Teams should be familiar with these criteria and the mechanisms through which to expedite referral.

### *Intervention*

5.24 Staff should be able to:

- communicate honestly and compassionately with those affected by cancer (see also Topic 3, *Face-to-Face Communication*)
- treat patients and carers with kindness, dignity and respect
- establish and maintain supportive relationships
- inform patients and carers about the wide range of emotional and support services available to them.

5.25 Appropriate interventions at Level 1 may prevent the development of more severe psychological problems, thereby affecting demand for services at Level 2 and beyond.

## **Level 2**

### *Assessment*

5.26 Professionals operating at this level should be able to screen for psychological distress at key points in the patient pathway, including:

- around the time of diagnosis
- during treatment episodes
- as treatment ends
- at the time of recurrence.

5.27 These assessments should be undertaken by designated professionals (such as nurse specialists, social workers and GPs), appropriately trained in screening for psychological distress. They should include the impact of cancer on people's daily lives, mood, family relationships (including sexual relationships) and work. Those undertaking an assessment should elicit worries and other feelings by establishing trust and listening in a permissive and non-judgemental manner. The assessment process itself may lead to the resolution of concerns; if not, it should result in an offer of appropriate psychological support. Patients experiencing significant psychological distress should be offered referral for specialist psychological support/intervention.

### *Intervention*

- 5.28 Level 2 involves psychological techniques such as problem solving delivered by trained and supervised health and social care professionals to manage acute situational crises at key points in the patient pathway. Clinical nurse specialists, among others, might be trained and supported to undertake assessments and to deliver relevant interventions.

## **Level 3**

### *Assessment*

- 5.29 Trained and accredited professionals should be able to differentiate between moderate and severe levels of psychological need and refer those with severe needs to mental health specialists.

### *Intervention*

- 5.30 Level 3 involves specific psychological interventions such as anxiety management and solution-focused therapy, delivered according to an explicit theoretical framework by a trained, accredited and supervised counsellor. It aims to manage mild to moderate levels of psychological distress including anxiety, depression and anger. Specific psychological interventions at this level are also appropriate for responding to mild to moderate cancer-related concerns such as worries about treatment, personal relationships (including sexual relationships), relationships with hospital staff and spiritual issues.

## **Level 4**

### *Assessment*

- 5.31 Mental health specialists should be able to assess complex psychological problems including severe affective disorders, personality disorders, substance misuse and psychotic illness.

### *Intervention*

- 5.32 Level 4 involves specialist psychological and psychiatric interventions delivered by mental health specialists to manage moderate to severe mental health problems. These include severe depression and anxiety, organic brain syndromes, severe inter-personal difficulties (including severe psychosexual problems), alcohol and drug-related problems, personality disorder and psychotic illness.

- 5.33 It may not always be possible to make a clear distinction between the boundaries of expertise of various professionals (particularly between Level 2 and Level 3), and there is likely to be some overlap between the levels.

- 5.34 Professionals offering different levels and types of psychological intervention should develop mechanisms to co-ordinate their service provision to ensure that interventions offered are most appropriate to a person's needs. This might include referral guidelines for each type (and level) of psychological intervention. If different specialists within a psychological support service work in an integrated way, referrals could initially be made to the overall service, with a subsequent system of assessment and triage used to decide the appropriate intervention. Final choice of treatment should be guided by patient preference, as there is considerable overlap in the mental health problems for which different therapeutic approaches can be effective.
- 5.35 Commissioners should ensure that emergency psychiatric services are available for patients who develop acute mental health problems and are a potential danger to themselves or others. They should also ensure that health care professionals have 24-hour, seven days a week access to advice for people caring for patients with acute mental health problems. This will typically be provided by the local mental health team.
- 5.36 Teams who care for people with cancer and those who care for people with mental health problems should endeavour to promote closer working relationships, developing mechanisms to enable them jointly to meet the needs of patients with cancer who develop mental health problems and those with mental health problems who develop cancer.
- 5.37 Appropriate facilities should be available for undertaking psychological assessments and interventions, reflecting the needs of patients and carers for privacy and comfort. In circumstances where patients are unfit to travel, specialist psychological/psychiatric interventions might be provided through domiciliary visits.
- 5.38 Psychological support services should have agreed processes for transfer of information within their service and with other services, teams and practitioners working with individual patients and carers. Information should include the findings from individual assessments, proposed treatment plans and outcomes of treatment. An agreed formal process for managing sensitive and private issues will be needed within teams.
- 5.39 Many patients suggest that the transition from active treatment to 'survivorship' is one of the most psychologically demanding phases of the patient pathway. Patients who have completed active treatment should be informed about the range of support services available and how to access them directly. In the first instance, this is likely to be through a GP or 'key worker', but it should be recognised that such needs can develop a considerable time after treatment has stopped.

- 5.40 Local service directories on supportive and palliative care should include information on psychological support services and the range of support groups available.

### **C.3 Workforce development: specific recommendations**

- 5.41 Practitioners responsible for the delivery of psychological care at each of the different levels should be identified.
- 5.42 An individual (or individuals) should be identified within each cancer site-specific and specialist palliative care team to take responsibility for providing Level 2 care (that is, screening for psychological distress and using simple psychological techniques).
- 5.43 Psychiatrists, psychologists, psychotherapists and counsellors should be identified at Cancer Network-level to provide care at Levels 3 and 4. If these staff have not previously worked with people with cancer and their carers, they will require additional training. The most appropriate providers of such training would be psychological care experts with extensive experience in cancer and who have worked with oncologists and palliative care specialists.
- 5.44 All staff providing psychological support within the recommended model will require training and ongoing supervision. Those working at the higher levels of the model should normally provide training, supervision and opportunities for continuing professional development for those operating at the lower levels.
- 5.45 Psychological specialists should also play a significant role in the development and maintenance of communication skills through teaching and training (see Topic 3, *Face-to-Face Communication*).

### **C.4 Research and development: specific recommendation**

- 5.46 Evaluative research is needed to determine which psychotherapeutic interventions are most effective and cost-effective for different groups of patients at different stages of the patient pathway.

## D. Evidence

### D.1 Overall benefit

5.47 While there is no formal evidence of the benefits of implementing the four-level model of psychological assessment and intervention, a considerable body of evidence supports the effectiveness of different elements within it. Of five systematic reviews in this area [A], one was equivocal, but four found evidence of benefit among those affected by cancer in relation to:

- reductions in psychological distress
- improvements in overall quality of life and other functional outcomes
- making the experience of having cancer more acceptable
- improvements in concordance with cancer treatments.

5.48 All people with cancer are likely to benefit from effective information-giving and sensitive communication throughout the patient pathway. About 15% of patients experience mild to moderate levels of distress at any one time in the first year after diagnosis of early disease and are likely to benefit from psychological techniques used by trained health professionals or a specific psychological intervention. Ten per cent experience more severe levels of psychological distress at any one time and are likely to benefit from specialist psychological or psychiatric intervention. The prevalence of all severities of psychological distress is somewhat higher for patients with advanced disease, so a greater proportion of these patients are likely to benefit from some form of psychological intervention.

### D.2 Assessment

5.49 There is fairly strong evidence that health care professionals have limited abilities in detecting the psychological needs of people with cancer. Such abilities can be developed through training focusing on the structure and coverage of individual assessments [B].

### D.3 Benefit of different approaches

5.50 An eclectic mix of psychotherapeutic and psychiatric interventions has been employed to meet the various needs of people with cancer. There is evidence that both individual [A] and group-directed [A] approaches realise benefits.



- 5.51 Interventions have been offered successfully in a variety of contexts, including home and hospital environments. A range of health, social and psychological care workers have been involved in the development and delivery of interventions, both as individuals [A] and working in teams [A]. Interventions delivered by psychiatrists, counsellors, psychologists, social workers, specialist nurses and psychotherapists have been subject to evaluation.
- 5.52 While the exact benefit derived from good communication and psychological interventions is difficult to quantify, counselling and specialist psychological and psychiatric interventions have been found to confer moderate to major benefit on those who receive them. They produce significant improvements in psychosocial functioning and overall quality of life for particular individuals [A].
- 5.53 There is strong evidence from meta-analyses to suggest that specialist psychological and psychiatric interventions (Level 4) confer benefit in reducing anxiety and depression and in bringing about emotional and functional adjustment. Psycho-pharmacological interventions are not covered by this Guidance, but services should ensure they follow the most effective practice.
- 5.54 Specific psychological therapies such as counselling and cognitive behavioural therapy (Level 4) have been evaluated in the context of cancer care with positive outcomes on a range of variables, including coping, anxiety, depression and self-esteem [A].
- 5.55 Psychological interventions at Level 2 consist of a diverse range of activities. The most effective include those designed to enhance self-care skills, provide information and enhance control, improve ability to adjust to life situations and problem solve [A]. Psycho-educational approaches, often drawing on a variety of techniques, have also been shown to bring benefit to patients who are suffering distress as a result of symptoms such as pain, nausea and breathlessness [A].

#### **D.4 Training and support**

- 5.56 Psychological support serves to enhance the ability of health and social care staff to provide good quality care. It has a role in managing occupational stress and in the recognition and prevention of 'burn-out'. There is general recognition that those providing psychological care need to be properly supervised, either in one-to-one situations or in groups, peer groups and work teams [C].



## E. Resource implications

- 5.57 Preliminary estimates of the cost of implementing the four-level model of psychological assessment and support are around £12.7m for England and Wales. The majority of this cost is composed of specialist staff including psychiatrists, psychologists, psychotherapists and counsellors required to provide more complex assessments and interventions (at Levels 3 and 4). Further work is recommended to produce a more robust cost estimate.
- 5.58 Individuals operating at Level 2 of the four-level model, who will be adopting this function as part of their existing roles, will require training, education, and ongoing support and supervision. Supervision and training by psychological care experts with extensive experience in cancer is also required for those delivering psychological care at Levels 3 and 4. These requirements will need to be prioritised and costed.

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# 6. Social Support Services<sup>K</sup>

## A. Introduction

- 6.1 The social impact of cancer is considerable<sup>1</sup>. People affected by cancer can have a range of needs for social care and support at different stages of the patient pathway. These include:
- emotional support, which may be derived from engaging in social activities, companionship or befriending, and making contact with health and social care professionals
  - help with personal care, such as bathing and dressing
  - advice on work and employment issues and assistance to secure financial support through, for example, help in making a benefit claim
  - help inside and outside the home, such as cleaning and shopping
  - practical aids, including wheelchairs and other equipment
  - help to care for children and other dependants such as older relatives.
- 6.2 The social implications of cancer may extend beyond the patient's immediate family and carers to relatives, friends, employers and work colleagues.
- 6.3 Social care encompasses:
- practical help
  - personal care for patients
  - preservation or enhancement of social networks
  - emotional support

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<sup>K</sup> The text for this topic area has been written in consultation with the Social Care Institute for Excellence (SCIE).

- income maintenance
- provision of information on local and national resources
- access to safe living environments which comply (at least) with minimum standards
- provision of respite care.

6.4 Support may be provided by family, friends and other social networks or by statutory and voluntary services. Councils with social service responsibilities assess individual need to provide or commission personal and domestic care in a person's home or a residential setting. They offer social work, occupational therapy and other elements of social care services in the home. Respite and day care, support groups, volunteer visitors, assisted transport and bereavement care may be provided by local authority, NHS or voluntary organisations.

6.5 Some needs may be fully addressed only by individuals or agencies outside the NHS. This Guidance is solely concerned with actions to be taken by people working within – or commissioned by – the health service. It is important that they recognise the social needs of patients and work, where appropriate, in close collaboration with social services departments. Although health and social care services have traditionally been poorly integrated, there is now a 'duty of partnership' on health authorities and councils (social services, housing and other council services). An appreciation of social needs on the part of health care providers can assist patients in adjusting to cancer and its practical demands, whether or not providers are able to directly meet these needs.

6.6 Patients and carers rarely experience a coherent, integrated system of social support. The number of agencies involved in planning and delivering services makes collaboration difficult and services are neither well known nor well understood by health care professionals. They may be uncertain about how to access social workers and staff shortages can make access difficult, leading to delays in getting assessments of social care need and subsequent access to services.

6.7 New targets for assessment and receipt of services have been announced and performance indicators for these targets will be published in October 2004. As a result of the Community Care (Delayed Discharges etc.) Act 2003<sup>2</sup>, social services will be required to provide services within a specified time or reimburse the NHS Trust for a patient's consequential extended stay in hospital. The Fair Access to Care Services initiative is addressing inequities in how eligibility criteria are defined and applied<sup>3</sup>.

- 6.8 Assessment of need can be difficult because some patients and carers may be reluctant to ask for help, arising from a desire to maintain independence and dignity or a concern that resources are limited. While professional interventions can be seen as supportive by some patients and carers, others may see them as intrusive.
- 6.9 Patients and carers often lack the skills and information to access and secure benefits. Health care professionals can sometimes undervalue the support available to patients and carers through friends and family, support groups and contacts with other people affected by cancer.

## B. Objectives

6.10 The objectives are to ensure that:

- social care needs of individual patients and carers are identified and addressed
- patients and carers experience a coherent and integrated system of social support, matched to their personal circumstances, to ease the social consequences of living with cancer
- practical and financial support is available to patients and carers where and when needed and in a way that is acceptable to them.

## C. Recommendations

### C.1 Overview

- 6.11 Commissioners and councils with social services responsibilities should establish a joint approach to the planning and delivery of care to ensure that services are organised to meet needs for social care.
- 6.12 Needs for social support should be elicited as an integral component of routine assessment, ideally undertaken with or by social care professionals.
- 6.13 The level of support offered to patients should be appropriate to their needs and should be acceptable to them, with 'signposts' to services outside the immediate health care environment.
- 6.14 Patients and carers should be offered assistance to obtain benefits for which they are potentially eligible by professionals who are informed and knowledgeable about the benefits system.

## C.2 Service configuration and delivery: specific recommendations

- 6.15 Patients with cancer need all agencies providing services, whether statutory or voluntary, to work together to deliver the care they need, when they need it. To this end, commissioners, working through Cancer Networks and councils with social services responsibilities, should establish collaborative working relationships. A range of options exists to strengthen the links between the NHS and social services at local level, and Cancer Networks should adopt the option most appropriate to their own local needs. The options for partnership working in England, provided by Section 31 of the Health Act 1999<sup>4</sup>, include pooled budgets, lead commissioning and integration of services. Cancer Networks should seek to build on existing arrangements for planning and commissioning services. In Wales, there is a joint duty upon Local Health Boards and local authorities to develop health, social care and well-being strategies with statutory and voluntary organisations and local people<sup>5</sup>.
- 6.16 Commissioners, working through Cancer Networks and councils with social services responsibilities, should ensure components of social support are available within the local Cancer Network and are accessible from all settings, whether patients' own homes or other accommodation. The appropriate balance of services may differ within each setting, but the main components are:
- practical support, including personal and domestic care
  - support to maintain independent living, including home adaptations and the provision of equipment
  - support to maintain employment status
  - access to individuals (such as welfare rights and benefits advisors) who can provide information and assistance in completing applications
  - services to assess the needs and protect the rights of vulnerable adults or children of a family member who has cancer, and to support people with cancer in caring for vulnerable adults or children
  - respite and day care in social and health care settings
  - care home placements
  - support for carers, including emotional and practical support.

- 6.17 Cancer Networks, in conjunction with commissioners and councils with social services responsibilities (Local Partnerships in Wales), should review the community equipment service with respect to patients' needs to ensure that necessary equipment can be delivered speedily and flexibly. *The NHS Plan*<sup>6</sup> for England set out the intention to achieve a single integrated community equipment service by 2004<sup>LM</sup>.
- 6.18 Teams should ensure that social care needs of each patient are identified as part of the initial routine assessment, and are then assessed on an ongoing basis. Assessments should cover the domains of personal care, relationships (including social contacts and involvement in leisure, work and learning), and immediate environment and resources (such as care of the home, housing, finances and access to local facilities and services). Local collaborative arrangements should ensure that assessments are undertaken by or with the help of social care professionals.
- 6.19 Based on these assessments, health care professionals providing day-to-day care to patients should arrange for a more specialist assessment, if necessary. Providers should ensure that health care professionals can readily access the most appropriately qualified professional to carry out specialist assessments.
- 6.20 Teams and health care professionals providing day-to-day care should ensure that the needs of families and carers are considered alongside those of patients (see Topic 12, *Support for Families and Carers*).
- 6.21 Providers, working with councils with social services responsibilities, should ensure that social workers can readily be accessed by patients, their families and health care professionals working in hospitals, hospices and primary care settings. Site-specific cancer and palliative care teams should be linked with named social workers or teams of social workers.
- 6.22 Health care teams in hospital, hospice and primary care settings should establish mechanisms to promote good working relationships with social services departments. Agreement should be reached about professional responsibility for different aspects of assessment, referral arrangements between professions or agencies, and information sharing.

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<sup>L</sup> As a result of the Community Care (Delayed Discharges etc.) Act 2003, the discretion for social services to charge for community equipment services has been removed since June 2003. This should make integration of NHS and social services community equipment services more straightforward.

<sup>M</sup> In Wales, the document *Fully Equipped*<sup>7</sup> was circulated to Health Authorities and NHS Trusts in July 2000. Trust Boards and Social Services Departments across Wales were asked to: review the management of their equipment services; incorporate the procurement of equipment into their overall supplies strategies; review existing arrangements to improve quality; and consider provision of a joint equipment service straddling health and social services.

- 6.23 As a result of the assessment process, teams should be able to help patients and carers locate additional sources of assistance and offer support and advice. Patients should be given clear advice on how to access different types of services.
- 6.24 Provider organisations should ensure that patients and carers have easy access to a range of information resources on social care appropriate to their age, culture and background. Providers might consider integrating information on sources of support with general cancer information services, local Patient Advice and Liaison Services (where they exist), and primary care and community information points such as libraries and citizens' advice services. Systems should be in place to direct patients to expert advice on benefits, including support in completing application forms.
- 6.25 Provider organisations should have arrangements to raise patients' awareness of different types of available support, including helplines, support groups, and other support offered by the voluntary sector (see Topic 2, *User Involvement in Planning, Delivering and Evaluating Services*).
- 6.26 Cancer Networks should ensure that service directories include information about local social services and statutory and voluntary sources of support. Networks in England should refer to *Fair Access to Care Services*<sup>3</sup> when reviewing and developing information about available services. In Wales, networks and multidisciplinary teams are responsible for delivering the national health care information strategy<sup>8</sup>. They are required to provide patients with information about services, including access to social services and sources of support.

### **C.3 Workforce development: specific recommendations**

- 6.27 All professionals likely to carry out an individual assessment will need to be skilled in assessment practice for social care. Workforce Development Confederations in England and the Workforce Development Steering Group in Wales, working in collaboration with Cancer Networks, should assess the level of need for training on social care needs among these health care workers.
- 6.28 Providers should ensure that staff are familiar with current working arrangements on obtaining specialist assessment and access to the full range of available social support services.

### **C.4 Research and development: specific recommendations**

- 6.29 Research is needed to determine the best ways to ensure effective co-ordination between social and health care services.



6.30 Research is needed to determine the particular role and contribution of social workers and volunteers in supportive and palliative care.

6.31 Research is needed to determine the particular role and contribution of different models of respite care for patients and families in supportive and palliative care.

## D. Evidence

6.32 Patients report unmet needs with respect to managing their daily life, emotions and changes in social identity<sup>1,9,10</sup>. Although descriptive studies are useful, the lack of outcome evaluations is regrettable. The body of evidence concerning the role and impact of various forms of social support for patients with cancer is small. With respect to assessment, there is evidence to suggest that setting up systems for the early identification of support needs can make a substantial difference to getting help to patients when they are first diagnosed [A]. Identifying the needs of terminally ill people in a sensitive manner can also help to increase the support offered to them [B].

6.33 Most research has focused on the effectiveness of interventions to provide support of various kinds. A large systematic review of research on the effectiveness of the palliative care team model found a small positive benefit on outcomes for both patients and carers [A]. Providing a variety of forms of care for terminally ill patients in their home makes it more likely that they will be able to die at home [B]. Care is also welcomed by carers, giving them a period of respite [B].

6.34 The impact of providing emotional support by various means to patients with cancer has been evaluated, and evidence for their effectiveness is presented in Topic 5, *Psychological Support Services*. Research shows that patients can be helped to cope with emotional reactions to terminal illness through group support sessions, gaining access to other patients with cancer who can serve as role models, and through the provision of a dedicated social worker [A]. In some cases, significant improvements have been found in the level of depression and other psychiatric symptoms.

6.35 There is a growing number of descriptions of services, which are valuable in providing information about the design and format of interventions and suggesting models of good practice [C]. Volunteers are often central to these initiatives, which include schemes designed to offer specialist benefits advice and assistance to access benefits<sup>11</sup> and schemes that offer information and support.



- 6.36 These should now be subject to evaluation. Acceptability needs to be considered at an early stage, as self-reliance and independence are important values, and barriers to accepting use of services need to be more fully understood<sup>13</sup>.

## E. Resource implications

- 6.37 The estimated national cost for the provision of detailed social care assessments and welfare benefits advice by social workers is £7.5m, of which 50% is assumed to be within specialist palliative care and 50% within general palliative and supportive care.
- 6.38 Social support services within specialist palliative care, including bereavement support and support within specialist in-patient units, day care centres, community and hospital support teams, are estimated to cost around £17.2m.
- 6.39 Cost of services that straddle NHS and social services sectors (such as respite care and transport costs) are excluded from the costings, as the Guidance cannot make firm recommendations on levels of service provision.
- 6.40 Education and training on the social needs of individual patients and carers is required for health care workers involved in carrying out front-line assessments. This will need to be prioritised and costed by Cancer Networks.

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# 7. Spiritual Support Services

## A. Introduction

- 7.1 The diagnosis of life-threatening disease has a profound effect on people who are ill and on their family and friends. Unsettling questions can often arise, such as ‘why is this happening to *me?*’, ‘what is the cause of this – is it my fault?’, ‘how can I make sense of my condition?’, and ‘how will I cope?’ Many questions relate to identity and self-worth as patients seek to find an ultimate meaning to their lives.
- 7.2 These questions re-emerge at various points in the patient pathway, but tend to be more focused when:
- new symptoms appear
  - side-effects of treatment become distressing
  - patients must adapt to changes in their lives which have emotional and social consequences
  - changes occur in relationships with key people.
- 7.3 Serious distress can arise for patients, as they can develop a deep sense of disconnectedness from themselves and from other people. Some people begin to re-examine their religious or other beliefs; they may re-affirm or abandon former beliefs and may find new ones.
- 7.4 Beliefs can be religious, philosophical or broadly spiritual in nature<sup>1,2</sup>. Formal religion is a means of expressing an underlying spirituality, but spiritual belief, concerned with the search for the existential or ultimate meaning in life, is a broader concept and may not always be expressed in a religious way. It usually includes reference to a power other than self, often described as ‘God’, a ‘higher power’, or ‘forces of nature’. This power is generally seen to help a person to transcend immediate experience and to re-establish hope<sup>3</sup>.

- 7.5 It follows that spiritual care should not be viewed solely in terms of the facilitation of appropriate ritual, which has implications for the assessment of spiritual needs. The nature of support needed can range from an informal sharing of ideas about the ultimate purpose of existence to the provision of a formalised religious ritual. The appropriate means of meeting need will vary by location, resources and skills available, and the nature of needs assessed.
- 7.6 Key issues in delivering effective spiritual and existential support to people experiencing illness or treatment or who are approaching death are:
- listening to the patient's experience and the questions that may arise
  - affirming the patient's humanity
  - protecting the patient's dignity, self worth and identity
  - ensuring that spiritual care is offered as an integral part of an holistic approach to health, encompassing psychological, spiritual, social and emotional care, and within the framework of the patient's beliefs or philosophy of life.
- 7.7 Spiritual needs of patients and carers may change over time and in response to clinical care. Other personal factors, such as family relationships, the provision of social support and relationships with faith leaders or others providing spiritual support, are also significant. As patients may express their needs only once, it is important for those assessing need to be highly attuned to the spiritual dimension of patient care. Some people have enduring spiritual difficulties requiring continuous help.
- 7.8 Most aspects of spiritual care can be offered in any setting: in a person's home or in hospitals, hospices, care homes or community hospitals. Care may be provided by:
- the patient's own family, friends or faith group
  - staff groups (of any discipline) within in-patient care settings or by a patient's GP/community nursing service, with additional support from a specialist palliative care service (see Topic 9, *Specialist Palliative Care Services*)
  - officially appointed faith leaders selected and trained to work within a cancer and palliative care setting, or a health care chaplain.

7.9 There are indications that spiritual needs are not being met within cancer services. For instance:

- patients have insufficient choice in people to whom they can turn for spiritual care, and may be unaware of choices available to them
- health and social care staff have insufficient awareness of how to access individuals who can provide spiritual care
- health and social care staff may be reluctant to call for chaplains' services or may not detect the need for spiritual support at key stages of the patient pathway; some may feel awkward and vulnerable when broaching spiritual issues with patients
- health and social care professionals may feel awkward about discussing, or even considering, their own spiritual needs as professional carers<sup>4,5</sup>
- in the hospice sector, there is disparate provision of spiritual care<sup>6</sup>
- within the hospital sector, there are insufficient numbers of chaplains to meet needs, as they are responsible for supporting all patients, not just those receiving cancer treatment or palliative care<sup>7</sup>.

## B. Objectives

7.10 The objectives are to ensure that:

- patients and carers receive support, if sought, to make sense of difficult life events through an exploration of spiritual and existential issues, including an effort to foster hope and promote well-being within an integrated care approach
- health and social care professionals are able to acknowledge spiritual issues among patients and carers and to respond in a flexible, non-judgemental and non-imposing way
- spiritual needs of staff are recognised, with support available to them in working in this area of care.

## C. Recommendations

### C.1 Overview

- 7.11 Patients with cancer and their carers should have access to different forms of spiritual support, appropriate to their needs.
- 7.12 Patients with cancer and their carers should have opportunities for their spiritual needs to be assessed at various points in the patient pathway, ensuring that spiritual elements of illness are taken into account.
- 7.13 Spiritual care for patients with cancer and their carers should be an integral part of health and social care provided in all care environments and should be open to similar levels of scrutiny and supervision as other aspects of non-physical care.
- 7.14 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 have up-to-date awareness of local community resources for spiritual care.

### C.2 Service configuration and delivery: specific recommendations

- 7.15 Providers and teams should ensure patients and carers are offered information about the resources available for spiritual care within a particular organisation or community, as well as information on how to access spiritual help and support.
- 7.16 Teams should ensure accurate and timely evaluation of spiritual issues is facilitated through a form of assessment based on recognition that spiritual needs are likely to change with time and circumstances. Assessment of spiritual needs does not have to be structured, but should include core elements such as exploring how people make sense of what happens to them, what sources of strength they can draw upon, and whether these are felt to be helpful to them at this point in their life.
- 7.17 Family and other carers may offer important components of spiritual care and, if the patient wishes, should be supported by providers and teams in doing so.
- 7.18 Some patients and carers may require the support of authorised health care chaplains, appointed in accordance with NHS national guidance<sup>8</sup>. For those patients living at home, and in particular those who are close to death, primary care teams should develop links with authorised faith leaders who can be accessed for advice and support.

- 7.19 Commissioners should ensure that multidisciplinary teams have access to suitably qualified, authorised and appointed spiritual care givers, capable of offering spiritual care in an open and flexible way and who can act as a resource for patients, carers and staff<sup>9-11</sup>. Representation may not be needed within every team, but all teams should be able to access people with a spectrum of skills and an agreed level of competence to support spiritual care.
- 7.20 Provider organisations should adhere to the framework of best practice in meeting the religious and spiritual needs of patients and staff outlined in NHS national guidance<sup>8</sup>. They should nominate a staff member to be responsible for liaison with local faith leaders. A health care chaplain/spiritual care giver would usually undertake this role.
- 7.21 Spiritual care should be seen as a responsibility of the whole team, while recognising that an individual may hold specific responsibility for ensuring its provision. This might be the role of a hospice or health care chaplain<sup>9-11</sup>. Individual team members responsible for offering spiritual care should contribute to the team's regular review of care plans, especially for those patients with an already identified spiritual need. Systems should be in place to ensure that patients are asked for their permission to pass on information about their spiritual needs to the chaplaincy service<sup>8N</sup>.
- 7.22 Providers within in-patient or day care facilities should ensure the availability of a dedicated and accessible 'quiet space' or room, suitably furnished in a way to allow for use by various faith groups or by those of no faith. The space/room should be equipped with religious equipment appropriate to the needs of faith groups likely to use it; examples include a portable cross, a table suitable for Christian use, communion vessels, worship books for different faith groups, prayer mats, washing facilities and a compass for identifying the direction of Mecca for use by Muslims. Careful local consultation is advisable before deciding on the form of accommodation.
- 7.23 Spiritual care does not stop at death. Providers should ensure that a suitable room (which may be off-site) is available where a deceased patient can remain while religious rituals are performed. This may need to be for 2-3 days in the case of a Jewish person dying on the eve of the Sabbath. Staff concerned with the management of the room should be respectful of the dead person. Providers should be able to observe the religious ritual of speedy burial of, for example, Muslim and Jewish people.

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<sup>N</sup> Service providers should familiarise themselves with guidance on securing explicit consent from patients to confidential information being shared with chaplains, including information on patients who are unable to offer consent, contained in Department of Health guidance on NHS Chaplaincy services<sup>8</sup>.

### **C.3 Workforce development: specific recommendations**

7.24 Skilled, sensitive and appropriate spiritual care can be provided by a variety of people, including volunteers, family members, health and social care staff and faith groups. It is essential that health and social care staff have the necessary skills, knowledge and support to deliver sensitive care. Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should ensure that staff working within supportive and palliative care services have access to:

- basic training in understanding the spiritual needs of patients and ways of assessing spiritual need
- training in the specific religious needs and rites of patients from different faith groups, including a sensitivity to the inter-relationship between culture, ethnicity and belief to avoid labelling and stereotyping
- appropriate spiritual care for their own needs which can arise in the course of their work
- local faith leaders from the community to ensure good continuity of care when patients are discharged; training opportunities should be available for local clergy, as not all are necessarily skilled, or confident, in this aspect of pastoral care<sup>12</sup>.

7.25 Commissioners and Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should also be mindful of the spiritual and religious care competencies for specialist palliative care developed by Marie Curie Cancer Care<sup>9</sup> (see Box 7.1).



## Box 7.1 Spiritual and religious care competencies for specialist palliative care<sup>9</sup>

### Level 1

#### **All staff and volunteers who have casual contact with patients and their families/carers**

This level seeks to ensure that staff and volunteers understand that all people have spiritual needs, and distinguishes between spiritual and religious needs. It seeks to encourage basic skills of awareness, relationships and communication, and an ability to refer concerns to members of the multidisciplinary team.

### Level 2

#### **All staff and volunteers whose duties require contact with patients and their families/carers**

This level seeks to enhance the competencies developed at Level 1 with an increased awareness of spiritual and religious needs and how they may be identified and responded to. In addition to increased communication skills, identification and referral of difficult needs should be achievable, along with an ability to identify personal training needs.

### Level 3

#### **Staff and volunteers who are members of the multidisciplinary team**

This level seeks to further enhance the skills of Levels 1 and 2. It moves into the area of assessment of spiritual and religious need, developing a plan for care and recognising complex spiritual, religious and ethical issues. This level also introduces confidentiality and the recording of sensitive and personal patient information.

### Level 4

#### **Staff or volunteers whose primary responsibility is for the spiritual and religious care of patients, visitors and staff**

Staff working at Level 4 are expected to be able to manage and facilitate complex spiritual and religious needs in patients, families/carers, staff and volunteers. In particular, they will deal with the existential and practical needs arising from the impact on individuals and families of illness, life, dying and death. In addition, they should have a clear understanding of their own personal beliefs and be able to journey with others, focused on people's needs and agendas. They should liaise with external resources as required. They should also act as a resource for the support, training and education of health care professionals and volunteers, and seek to be involved in professional and national initiatives.

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- 7.26 Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) should ensure that all core staff within specialist palliative care teams are sufficiently competent to assess and address spiritual issues (see Topic 9, *Specialist Palliative Care Services*). Training programmes in supportive and palliative care for senior health care professionals should include study of the theory and practice of spiritual care.

#### **C.4 Research and development: specific recommendations**

- 7.27 Research is needed to promote understanding of how spiritual needs and sources of support of different patient groups evolve over time and how spiritual concerns are best assessed and measured.
- 7.28 Research is needed to determine best ways of providing spiritual support for different patient groups in different settings and at different stages of disease.

### **D. Evidence**

- 7.29 There appears to be growing interest in the relationship between spiritual support and health, but relatively little research has been carried out in this area. Some has centred on the nature of provision of spiritual support for patients. Hospitals and hospices appear to be changing the nature of their arrangements for spiritual support in line with changes in the religious beliefs of the wider population. There is an increasing use of multi-faith/quiet rooms as spiritual focal points in preference to traditional chapels, and expansion of the role of chaplains/spiritual care givers from one that is purely religious [B]. There is also interest in developing provision for spiritual support within the care home sector [B].
- 7.30 Patients have been found to have needs for spiritual support, some of which are rooted in formal religion and some arising from a broader interpretation of spirituality. The differentiation, but inter-relatedness, of religion and spirituality is becoming more widely accepted [B]. Many patients view spirituality as a mechanism for coping with their health [B].
- 7.31 The question of which professionals should provide spiritual care to patients has also received some attention. Nurses are seen to be in a key position to respond to patients' needs for spiritual care, but often view it in terms of formal religion and therefore refer patients to clergy.

- 7.32 It has been argued that multidisciplinary teams for palliative care should include chaplains/spiritual care givers [B], and standards that relate to chaplaincy services within the context of palliative care have been published<sup>10</sup>. Measurement tools to inform the development of assessment approaches to spiritual care in clinical practice have been developed and tested<sup>13</sup> [B].
- 7.33 Research is beginning to address the relationship between spiritual belief and health outcomes for patients. Some studies have found a positive relationship in terms of risk of disease, survival times and coping with bereavement, but there is also evidence in the opposite direction where belief strength is ill formed [B]. Some research including patients with cancer suggests that spirituality is an important contributor to both physical well-being and quality of life [B]. A UK cohort study concluded that people who profess stronger spiritual beliefs resolve their grief more rapidly and completely after the death of a close person than do people with no spiritual belief <sup>14</sup> [B]. Evidence on the impact of prayer on health outcomes is inconclusive [A].
- 7.34 There are some examples of good practice with respect to defining competencies and standards in this area which could be drawn upon to help develop education and training initiatives for members of multidisciplinary teams<sup>9</sup>.

## E. Resource implications

- 7.35 Spiritual support services are required to provide support within specialist in-patient units, as part of day care services, and in community and hospital support teams. The total national future cost of provision is estimated at around £4.1m, around £2.5m higher than estimated current expenditure.
- 7.36 An additional resource implication will arise from training and education needs of health and social care professionals to enable them to carry out assessments of spiritual needs of patients and their carers.

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# 8. General Palliative Care Services, including Care of Dying Patients

## A. Introduction

- 8.1 Health and social care professionals providing day-to-day care form the mainstay of support for patients with advanced cancer, their families and carers. Support is offered in community and hospital settings and the personnel involved includes:
- GPs and other members of primary care teams
  - community nurses
  - care home staff
  - doctors and nurses in hospitals and hospices
  - allied health professionals in the community and in hospitals
  - social workers
  - general and community dental practitioners
  - participants and facilitators in self-help and support groups.
- 8.2 These people assess patients' and families' needs for care and support and meet them within the limits of their knowledge and competence. They should seek advice from – or refer to – specialist services when necessary.
- 8.3 General palliative care is a core aspect of care and at its best includes the provision of:
- information for patients and carers, with 'signposting' to relevant services
  - accurate holistic assessment of patient needs

- co-ordination of care teams in and out of hours and across boundaries of care
- basic levels of symptom control
- psychological, social, spiritual and practical support
- open and sensitive communication with patients, carers and professional staff.

8.4 Training, supporting and enabling health and social care professionals providing day-to-day care are important in ensuring the most effective support is provided to patients in all settings, including those where little or no specialist service is available. Palliative care may form only a small part of the normal workload of these professionals. Some may not have had access to education and training in palliative care, and some may not be aware of the expertise available from specialist palliative care services. As generalists deliver the majority of care, measures to enable them to provide a quality service are to be encouraged.

8.5 Although many patients and carers report high levels of satisfaction with the care they receive, inadequacies in care are also frequently reported. These include:

- inadequate assessment of patients' needs
- poor co-ordination of care
- poor face-to-face communication
- lack of information
- inadequate psychological, social and spiritual support.

8.6 Specific problems in the delivery of care in the community in some areas include:

- a lack of 24-hour, seven days a week district nursing services
- a lack of systems to organise and optimise general palliative care
- inadequate anticipatory care and discharge planning
- inadequate communication between daytime and out-of-hours medical services

- inadequate access to pharmacy services outside normal working hours
- inadequate access to equipment needed by patients at home
- lack of availability of and access to specialist services, and lack of clarity about their benefits.

### *Care of dying patients*

- 8.7 The care given in hospitals, at home and in care homes to patients who are dying can be suboptimal. This may be due to staff failing to recognise or acknowledge impending death. It may also be due to lack of education and training in best practice in initial assessment and care, ongoing assessment and care, and care after death.
- 8.8 Hospices have developed a 'model of excellence' for care of dying patients. Improvements in the provision of community care, including the organisation of services, symptom control, and psychological, social and spiritual support, may lead to fewer crises, fewer hospital admissions, more rapid discharges, and more patients being enabled to die in the place of their choice.

## B. Objectives

- 8.9 The objectives are to ensure that:

- all patients with advanced cancer receive high-quality care at all times and in all settings, including symptom control and the provision of psychological, social and spiritual care
- people's preferences on the location of care are followed, whenever possible.

### *Care of dying patients*

- all patients have a dignified death, with family and other carers adequately supported during the process.

## C. Recommendations

### C.1 Overview

- 8.10 All patients with advanced cancer should have their physical, psychological, social and spiritual needs, and their preferences for the nature and location of care, assessed on a regular basis.
- 8.11 Health and social care professionals providing day-to-day care to patients should know when to seek advice from, or refer to, specialist palliative care services.
- 8.12 Ongoing care of patients with advanced cancer from health and social care professionals providing day-to-day care should be based on locally agreed protocols and guidelines delivered within the context of a managed system or pathway.
- 8.13 Staff providing general palliative care should be trained in identifying needs of patients and carers and in general principles and practice of palliative care.

#### *Care of dying patients*

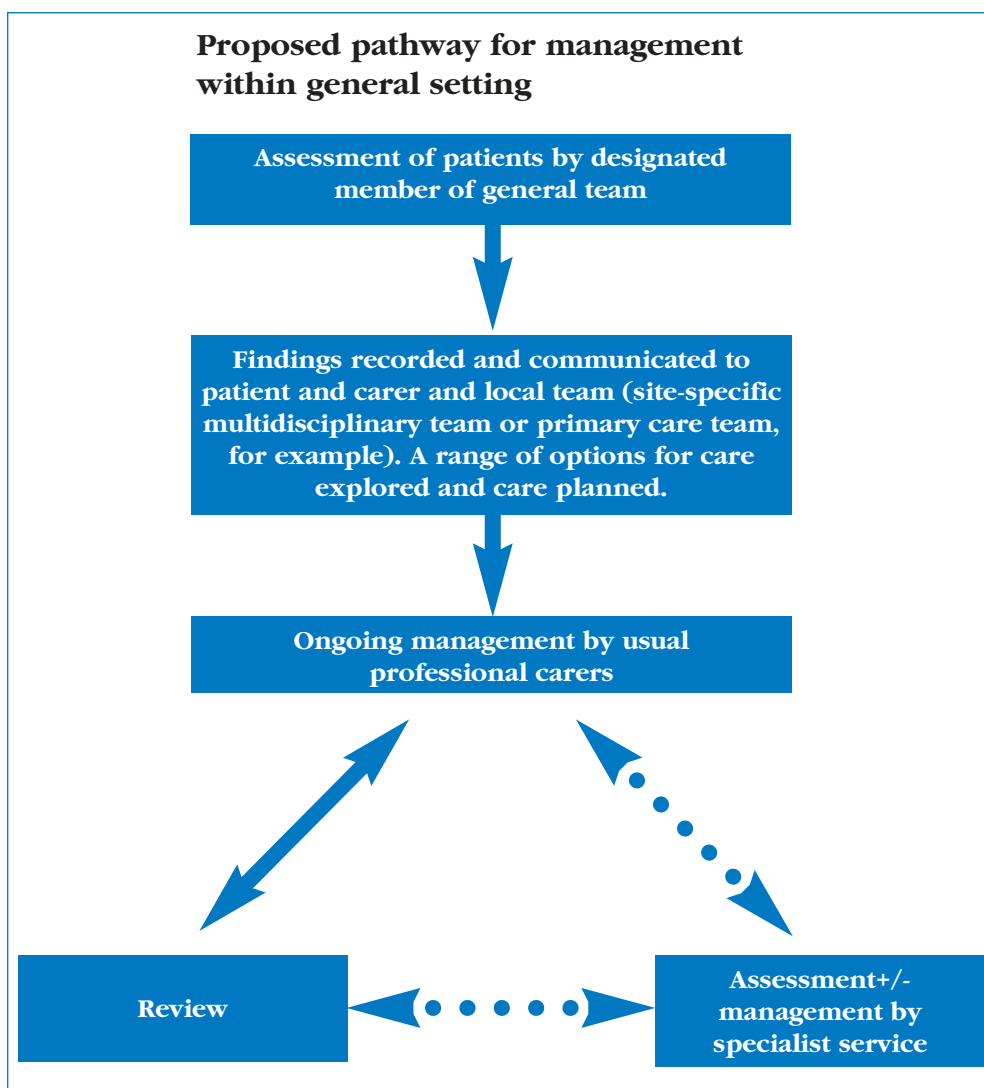
- 8.14 When death is imminent, particular attention should be given to assessing and accommodating the wishes of patients, families and other carers. Staff should be trained in best practice on caring for dying patients and measures should be in place to ensure that integrated care is delivered.

### C.2 Service configuration and delivery: specific recommendations

- 8.15 All patients with advanced cancer should have their needs systematically assessed on a regular basis across the domains of physical, psychological, social and spiritual needs, using agreed assessment tools. As needs can change rapidly, re-assessment will be necessary at frequent intervals.
- 8.16 Assessments should be made by health care professionals who have received further education and training in palliative care (Figure 8.1). Where this is not possible, assessments should be undertaken either solely by the local specialist palliative care team or in conjunction with them.
- 8.17 The findings of an assessment, including the principal needs of patients and carers, should be recorded in the patient's records and formally discussed within the team providing care.
- 8.18 Discussion with the local specialist palliative care service (community, hospice or hospital based, as appropriate) should allow joint decisions to be made on whether further involvement by the specialist team is required at this point in the patient pathway.



**Figure 8.1**



8.19 Cancer Network-wide eligibility criteria for specialist palliative care should be developed to inform this decision-making process. Cancer Networks might consider implementing assessment tools to indicate when referral to specialist palliative care could be of benefit.

8.20 Cancer Network-wide protocols and guidelines should be developed and implemented for symptom control and palliative interventions for common emergencies such as spinal cord compression, superior vena cava obstruction and hypercalcaemia. These should be subject to regular audit.

#### *Care of dying patients*

8.21 Cancer Network-wide protocols and guidelines should be developed, including criteria for referral to specialist palliative care services and the management of complex symptoms in patients who are dying and their carers. These should be subject to regular audit (see Topic 9, *Specialist Palliative Care Services*).

### Community-specific issues

- 8.22 In partnership with relevant stakeholders, commissioners should identify the full range of palliative care service provision, both generalist and specialist, in their locality. Commissioners have a responsibility to commission fully NHS-funded continuing care packages which cover all an individual's care needs, including palliative care (where needed). This could be provided in any setting. In commissioning palliative care provision within care homes, they should ensure that the quality of care<sup>O</sup> reflects the level of care defined in the care home's Statement of Purpose.
- 8.23 Commissioners and providers should work together to develop policies for the provision of out-of-hours palliative care to patients with cancer. This should be underpinned by an assessment of local needs and deficiencies.
- 8.24 Commissioners should ensure that medical and nursing services are available on a 24-hour, seven days a week basis for patients with advanced cancer living at home. District nursing services should have the capacity to provide intermittent visiting, day or night, which can be increased in frequency as required.
- 8.25 Where 24-hour, seven days a week district nursing services are not available, alternative means of providing patients with advanced cancer with access to qualified nurses around the clock should be agreed between commissioners and the Cancer Network. Account should be taken of the likely needs of patients at night, so that an appropriate balance of qualified nurses (who can undertake specialist interventions in a patient's home) and care assistants (who can stay for prolonged periods in the home) can be reached.
- 8.26 Teams should develop mechanisms to ensure the transfer of relevant clinical information about patients between those providing care 09.00-17.00, Monday-Friday, and those providing services and care out of hours using, for instance, paper or electronic handover forms<sup>P</sup>.

<sup>O</sup> Commissioners will need to make reference to bodies responsible for setting national standards in this area to ensure guidance on quality is relevant and converges with national standards.

<sup>P</sup> These mechanisms should be consistent with Standard 10 of the *Quality Standards in the Delivery of GP Out of Hours Services*<sup>1</sup>, which states: 'There should be a system for transmission of information about patients with special needs (including terminal care, violent and vulnerable patients) from the practice to the provider.' The standards were developed subsequent to publication of the Carson Report, *Raising Standards for Patients. New partnerships in out-of-hours care*<sup>2</sup>, published by the Department of Health in 2000.

8.27 In line with other measures<sup>Q</sup>, teams should agree means of identifying patients with advanced cancer who have care needs through, for example, establishing a register or database. An agreed framework or managed plan of care provided by the primary care team, such as the Gold Standards Framework<sup>3,4</sup>, is also recommended. Box 8.1 outlines key components of best practice in community palliative care.

### Box 8.1 Key components of best practice in community palliative care<sup>3,4</sup>

- Patients with needs for palliative care are identified according to agreed criteria and a management plan discussed within the multidisciplinary team.
- These patients and their carers are regularly assessed using agreed assessment tools.
- Anticipated needs are noted, planned for and addressed.
- Patient and carer needs are communicated within the team and to specialist colleagues, as appropriate.
- Preferred place of care and place of death are discussed and noted, and measures taken to comply, where possible.
- Co-ordination of care is orchestrated by a named person in a practice team.
- Relevant information is passed to those providing care out of hours, and anticipated prescribed drugs left in the home.
- Deleted in 2019 (see Update information)
- Carers are educated, enabled and supported, which includes the provision of specific information, financial advice and bereavement care.
- Audit, reflective practice, development of practice protocols and targeted learning are encouraged as part of personal, practice and provider organisation development plans.

<sup>Q</sup> As part of its work on minimum data sets, the National Health Service Information Authority (NHSIA) for England is developing practice-based registers for cancer: see [www.nhsia.nhs.uk/phsmi/datasets](http://www.nhsia.nhs.uk/phsmi/datasets). Cancer is included as one of the disease areas within the clinical domain of the 'Quality and Outcomes Framework' (QOF) of the new General Medical Services contract, which requires practices to produce a register of all cancer patients, defined as: 'a register of patients with a diagnosis of cancer, excluding non-melanotic skin cancers, from 1st April 2003'. The implementation of the QOF in Wales is being supported by two software products from MSDi - 'Clinical Audit' and 'Contract Manager'. These products will support practices in ensuring they have high quality, valid and accurate registers to meet the QOF requirements.

- 8.28 Commissioners should ensure that equipment needed to enable patients to continue living in the community is available within an agreed timescale, and is removed promptly and sensitively when no longer required (see Topic 6, *Social Support Services*).

### **Hospital-specific issues**

- 8.29 If a patient is to be cared for in a location in which there are no health professionals with post-registration experience or training in palliative care, the hospital specialist palliative care team should be informed. Assessment of the patient's needs will determine the level of involvement required by the specialist palliative care team.
- 8.30 Lines of responsibility for out-of-hours medical care should be agreed and recorded in the patient's notes. Ways of accessing advice from specialist palliative care staff should also be documented.
- 8.31 The discharge of a patient from secondary care should ideally occur only when all the necessary support services are in place. Providers might wish to identify a designated discharge co-ordinator to liaise with relevant services.
- 8.32 Patients and carers should be aware of the person or service to contact if problems arise following discharge.

### **Care of dying patients**

- 8.33 Provider organisations should ensure that managed systems to ensure best practice in the care of dying patients are implemented by all multidisciplinary teams.

### Box 8.2 Best practice in the last hours and days of life<sup>7</sup>

- Current medications are assessed and non-essentials discontinued.
- 'As required' subcutaneous medication is prescribed according to an agreed protocol to manage pain, agitation, nausea and vomiting and respiratory tract secretions.
- Decisions are taken to discontinue inappropriate interventions, including blood tests, intravenous fluids and observation of vital signs.
- The ability of the patient, family and carers to communicate in English or Welsh is assessed.
- The insights of the patient, family and carers into the patient's condition are identified.
- Religious and spiritual needs of the patient, family and carers are assessed.
- Means of informing family and carers of the patient's impending death are identified.
- The family and carers are given appropriate written information.
- The GP practice is made aware of the patient's condition.
- A plan of care is explained and discussed with the patient, family and carers.

8.34 Providers should ensure the environment in which dying patients are cared for is conducive to the needs of patients and carers. Issues that merit attention include consideration of the means to achieve:

- privacy around the bed area
- washing, bathing and toilet facilities suitable for the needs of extremely frail people
- a quiet and restful environment free from intrusive background noise
- sufficient space to allow relatives and friends to sit comfortably with the patient

- facilities for relatives to stay overnight in a location close to the patient, to receive comfort when distressed and to have time away from the bedside
- facilities for children who are relatives to be with the dying patient.

8.35 The patient's wishes concerning the location of care and place of death should be sought and respected. Providers should ensure that flexible systems are in place to obtain rapid and safe discharge of patients who wish to die at home.

8.36 Commissioners should ensure that continuous support can be provided for patients in their homes as end of life approaches, in compliance with the wishes of patients and carers. This may involve qualified nurses and/or trained carers, according to the patient's needs.

8.37 Primary Care Organisations should make arrangements to ensure 24-hour, seven days a week access to medications that may be required in a dying patient's home. They should work within existing recommendations for making medications available to patients at the time and place of consultation<sup>2</sup> (in this case, the patient's home). This could be effected through:

- pre-emptive planning
- leaving a supply of appropriate prescribed medications in the home
- making prescribed medications available to out-of-hours providers through the provision of 'palliative care bags'<sup>8</sup> for identified patients.

### **C.3 Workforce development: specific recommendations**

8.38 Cancer Networks, working with Workforce Development Confederations in England (and the Workforce Development Steering Group and NHS Trusts in Wales) should identify priorities for training staff in palliative care. In England, this would require building on the Department of Health-funded district nurse training programme. The aim should be to ensure that all patients with advanced cancer can be cared for by teams with at least one member who has undergone post-registration education and training in palliative care.

- 8.39 Education and training should be designed to enable health and social care professionals to conduct assessments of needs, including the care of dying patients, deliver general palliative care services and recognise when to seek advice or refer to specialist services. They should include staff working in all care settings. Staff require designated time to fulfil their education and training requirements.

#### *Care of dying patients*

- 8.40 Provider organisations should work with Workforce Development Confederations in England (the Workforce Development Steering Group in Wales) to ensure that all relevant staff are educated and trained in best practice regarding the care of dying patients.

### **C.4 Research and development: specific recommendations**

- 8.41 Evaluative research is needed to determine the most cost-effective ways to train, sustain the skills of and provide guidance and protocols in palliative care for GPs, district nurses and hospital and care home staff. This should include the development and evaluation of tools for assessing individual patients' and carers' needs and training in approaches to the diagnosis of dying and symptom control.
- 8.42 Research is needed to determine cost-effective ways of providing general palliative care to patients and families out of hours.
- 8.43 Evaluative research is needed to determine the best models of multidisciplinary working between generalist and specialist palliative care to ensure high quality care for all patients; this includes access to services and support for specific patient groups, particularly older people with cancer.

## **D. Evidence**

### **D.1 Assessment**

- 8.44 Survey evidence suggests that symptoms and concerns in patients with advanced cancer, whether in a hospital or the community, are often poorly assessed and controlled in the general setting<sup>9,10</sup>. Better methods of assessment and the use of guidelines and protocols may improve this situation [B].

- 8.45 Performing structured assessments and seeking the views of patients receiving care have been shown to increase patient satisfaction with communication and decision making [A]. Combining detailed assessment with individualised interventions has been demonstrated to improve both physical and psychological status [A]. Assessment tools can also be of value in improving diagnostic skills (such as distinguishing neuropathic pain)<sup>11</sup>, communicating to relatives and within teams, monitoring patient progress, and stimulating referral to specialist palliative care services<sup>12</sup> [B].

#### *Care of dying patients*

- 8.46 To care for dying patients, it has been found that dying needs to be diagnosed<sup>13</sup>. Recognising the key signs and symptoms of dying is acknowledged as an important clinical skill, but this can be a complex process. Clinicians are sometimes reluctant to make the diagnosis if any hope of improvement exists, and are even more reluctant if no definitive primary diagnosis has been made<sup>7</sup>. Reluctance on the part of health care professionals may stem from that fact that many may not have received education and training in how to care for dying patients, and therefore feel unprepared and helpless. Once dying has been diagnosed, the team can refocus care appropriately for patients and their relatives.

## **D.2 Advice from, and referral to, specialist palliative care**

- 8.47 The involvement of specialist staff in the support and education of health care professionals, particularly nurses, has been shown to facilitate communication between patients and professional carers providing day-to-day care and to enhance symptom management [A]. Topic 9, *Specialist Palliative Care Services*, gives further evidence on outcomes associated with the involvement of specialist palliative care teams.
- 8.48 Audit and observational data suggest that those managing patients with advanced cancer may not always follow guidelines and protocols on, for example, pain control [B]. There is, however, very strong general evidence that the use of clinical guidelines and protocols can improve the processes and outcomes of care<sup>14</sup> [A]. Specifically, the introduction of clinician-developed guidelines on pain has been shown to improve pain management when introduced as part of a broader education programme [A].
- 8.49 The use of 'eligibility criteria' for referral to specialist palliative care services is felt to help clarify interlinking and co-working between generalist and specialist teams<sup>15</sup> [C].



### *Care of dying patients*

8.50 Deleted in 2019 (see Update information)

8.51 Deleted in 2019 (see Update information)

## **D.3 Access to services**

8.52 Studies confirm that many people would prefer to die at home, yet only about 25% of people with cancer do so, with approximately 50% dying in hospital and the remainder dying in a hospice or care home<sup>17</sup>. It is also recognised that patients change their minds about preferences over location of care and place of death.

8.53 It is postulated that a variety of factors leads to this situation, but a prime issue is believed to be the dramatic reduction in patient and carer support out of hours. This includes lack of out-of-hours nursing care within the home, medications and equipment being unavailable in the location and at the time required, and difficulties that result from GP services provided by co-operatives and deputising services<sup>9,18,19</sup>.

8.54 Provision of 24-hour, seven days a week nursing care at home, compared to usual care, appears to decrease the need for out-of-hours GP visits. It is not possible to conclude that intensified nursing care increases the likelihood of dying at home [A], but studies demonstrate support for the contention that standard home care alone may be insufficient to deliver the additional interventions required by patients dying at home [A].

## **D.4 Education and training**

8.55 Survey data demonstrate that although many health care professionals are extremely competent and inspire high satisfaction levels among carers<sup>20</sup>, some have inadequate knowledge and feel ill-prepared to care for patients in the advanced phase of illness<sup>21,22</sup> [B].

- 8.56 The benefits of providing education and training to enhance knowledge, skills and competence of health care professionals are universally acknowledged. In the domain of palliative care, improvements are likely to be seen in a number of areas, including:
- increased confidence and competence when dealing with physical and psychological concerns
  - increased patient and carer satisfaction
  - timely and appropriate referral to specialist services<sup>23</sup>.
- 8.57 The Macmillan GP Facilitator Programme in cancer and palliative care is a peer educational programme that funds GPs with experience in palliative care to work with practices in their own localities. There are around 80 GP facilitators in the UK; their role includes making practice visits, undertaking local needs assessment, liaison with local specialist services and participation in strategy development. An evaluation in England found that a strength of the programme was the enhancement of GPs' positive attitudes towards specialist services, improving communication between primary care and specialist palliative care<sup>24</sup> [B].
- 8.58 Programmes of education and training, particularly in pain management, have been shown to lead to improvements in knowledge, attitudes and clinical behaviours of doctors and nurses [A].
- 8.59 The Gold Standards Framework<sup>3,4</sup> [C] aims to improve the quality and organisation of palliative care provided by the whole primary care team by developing the practice-based organisation of care of dying patients. The framework focuses on seven key tasks - optimising continuity of care, teamwork, advanced planning (including out-of-hours), symptom control, and patient, carer and staff support. Early evaluation data are becoming available<sup>25</sup>, with findings confirming an increase in patients dying in their preferred place and improved quality of care as perceived by the practitioners involved<sup>26</sup>.
- 8.60 The introduction of the Preferred Place of Care (PPC) plan is a new initiative by Lancashire and South Cumbria Cancer Network<sup>27R</sup>. The key aim is to assess needs and resources for patients who wish to die at home. It also provides a vehicle to initiate discussions about death and dying with patients and carers and a mechanism to identify and meet their expressed

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<sup>R</sup> For further information on this project, contact Chris Pemberton, Project Facilitator: [Chris.Pemberton@clha.nhs.uk](mailto:Chris.Pemberton@clha.nhs.uk)

preferences. Use of the PPC assists in the identification of resource deficits and the development of cross-agency provision. It invites patients and carers to comment on their experiences of care, thereby including users in service provision development.

### *Care of dying patients*

8.61 Deleted in 2019 (see Update information)

## E. Resource implications

- 8.62 The cost of implementing an agreed framework or managed plan of care provided by the primary care team, such as the Gold Standards Framework<sup>3,4</sup>, and ensuring that managed systems to achieve best practice in care of dying patients, are implemented by all clinical teams is estimated to have set-up costs of £2.8m in the first year and £2.2m per annum running costs nationally.
- 8.63 The full cost of out-of-hours district nursing service provision in all networks is estimated to be £89.9m. Some Cancer Networks, however, already provide evening and/or night services. Based on estimates of current provision, the incremental cost of ensuring that Cancer Networks not currently providing this service can offer full coverage in the future is £33.2m. Further work is recommended to produce a more robust cost estimate.
- 8.64 Education and training programmes are required for health and social care professionals working in all care settings, including care homes, community hospitals and acute hospitals, to enable them to conduct assessments of palliative care needs, deliver general palliative care services, and recognise when to seek advice or refer to specialist services.

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# 9. Specialist Palliative Care Services

## A. Introduction

- 9.1 Many patients with advanced cancer experience complex problems<sup>S</sup> – physical, psychological, social and spiritual – which generalist services in hospitals or the community cannot always deal with effectively. Families and other carers face many issues and concerns for which they may need expert support during the lives of patients and in bereavement (see Topic 12, *Services for Families and Carers*).
- 9.2 In response to these needs, specialist palliative care services have been established across the country over the past three decades. These are provided by statutory and voluntary organisations and cover the spectrum of community, hospice and hospital settings. The voluntary sector plays a significant role in providing specialist palliative care in people's homes, in in-patient, outpatient and day care specialist units, and in providing support to generalist teams in hospitals and care homes.
- 9.3 Many services specialise in providing aspects of palliative care to patients and their carers, but are not full 'specialist palliative care services' as defined here. One example is specialised home nursing services for people who are terminally ill. A spectrum of services is available, ranging from generalist services such as those provided by a GP team, through 'specialised' services such as the home nursing example referred to above, to a full multidisciplinary 'specialist' palliative care service operating in hospital, hospice or the community.
- 9.4 The availability of specialist palliative care services is variable throughout the country. A survey undertaken on behalf of the Department of Health<sup>1</sup> revealed major variations between regions in the provision of specialist (hospice) palliative care beds and palliative care nurse specialists and the availability of hospital palliative care teams.

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<sup>S</sup> Complex problems are defined as those that affect multiple domains of need and are severe and intractable, involving a combination of difficulties in controlling physical and/or psychological symptoms, the presence of family distress and social and/or spiritual problems. They also exceed the capacity and competence of providers to meet the needs and expectations of the patient and carers.

- 9.5 Only 55% of hospital services in England have a full multidisciplinary palliative care team which includes consultants and nurse specialists, according to a 2001 appraisal of services against the National Cancer Standards. Fewer than half of the 176 teams appraised were able to provide 24-hour access to advice<sup>2</sup>. Yet about half of all patients with cancer die in acute hospitals<sup>3</sup>.
- 9.6 Concerns have been expressed that the needs of people with cancer in care homes are not being adequately met. This may be due partly to insufficient staff to meet the needs of dying patients and lack of staff training. Community specialist palliative care services vary considerably in their staffing levels, affecting their ability to provide direct patient support or advice to care home staff at weekends and outside the hours of 09.00-17.00, Monday-Friday.
- 9.7 Concerns have also been expressed that patients' needs for specialist palliative care services are not always adequately assessed and that, even when they are, referrals are not offered early enough. This can cause unnecessary suffering to patients.
- 9.8 Those involved in specialist palliative care services have an important function in providing education and training on the principles and practice of palliative care. This should be provided to the wide range of generalists who offer care to people with advanced, progressive, life-threatening disease and their carers (see Topic 8, *General Palliative Care Services, including Care of Dying Patients*). These specialists also have a role in research and audit.

## B. Objectives

- 9.9 The objectives are to ensure that:
- patients who may benefit from specialist palliative care services are identified and referred without delay
  - patients who need specialist palliative care services can access services when they need them from hospitals, hospices and within the community.

## C. Recommendations

### C.1 Overview

- 9.10 All patients with advanced cancer should have their physical, psychological, social and spiritual needs assessed by a competent health care professional (see Topic 8, *General Palliative Care Services, including Care of Dying Patients*).
- 9.11 Specialist palliative care teams should work closely with generalist providers to ensure that patients are offered access to specialist services at the right point in the patient pathway.
- 9.12 All specialist palliative care service providers should have agreed mechanisms for co-ordinating care with those referring people to them and have agreed eligibility criteria for referral.
- 9.13 A range of specialist palliative care services should be available across a Cancer Network with levels of service provision sufficient to meet the needs of the local population, taking account of cancer death rates, deprivation levels and other key factors.
- 9.14 These services are likely to include, as a minimum:
- multidisciplinary specialist palliative care teams providing assessment, advice and care for patients in all locations
  - specialist in-patient facilities (such as hospice beds) for patients with complex problems that cannot be managed adequately in other settings
  - bereavement support services (see Topic 12, *Services for Families and Carers, including Bereavement Care*).
- 9.15 Each specialist palliative care service should have a range of staff who can provide the expertise needed by patients.
- 9.16 Across a Cancer Network, there should be sufficient staff to enable the delivery of care on a 24-hours, seven days a week basis and to contribute as needed to the education and training of generalist staff.
- 9.17 All providers of specialist palliative care services within a Cancer Network should develop and implement guidelines against which assessment, treatment and care of patients can be audited and monitored.



## C.2 Service configuration and delivery: specific recommendations

### Organisation and planning of services

9.18 Commissioners, working through Cancer Networks, should ensure they provide an appropriate range and volume of specialist palliative care services to meet the needs of the local population. There is a lack of evidence to support specified levels of service provision, such as the number of specialist in-patient beds required per million population. Commissioners should plan services flexibly around the needs of patients, recognising that this can be achieved in more than one way.

9.19 The levels and nature of provision will depend on a number of factors, including:

- local demography (such as age, levels of social deprivation and ethnicity)
- the number of cancer deaths
- the views of local service users
- the nature, extent and distribution of existing services.

Volumes of service are interdependent; for example, an increase in the resources of a community specialist palliative care team may lessen the need for in-patient care. In addition to comparing local services with national averages and services elsewhere, Cancer Networks should carry out needs assessments, including audits of patients who meet eligibility criteria but are unable to access services. These data may provide the strongest case for service expansion.

9.20 The range of services provided by specialist multidisciplinary palliative care teams should include:

- assessment, advice and care for patients in all settings
- specialist in-patient facilities (hospices or hospitals) for patients with complex problems who would benefit from the continuous support of a multidisciplinary specialist palliative care team.

9.21 Where specialist day care facilities are already established, commissioners and providers should agree their objectives and the types of interventions that should be offered within them. Commissioners may wish to extend this form of provision, but only after careful consideration of the interface of such facilities with other supportive and palliative care services.

9.22 Services should have the capacity to provide intensive co-ordinated home support to patients with complex needs who wish to stay at home. Such support may be needed to respond to a crisis in the care of a patient at home, for the last few days of terminal care, or for longer periods. A range of co-ordinated inputs will be required, but will generally involve:

- the specialist palliative care team
- practical nursing care and support for extensive periods throughout the day and night
- the patient's GP
- support from other services, such as those provided by social services departments.

9.23 To achieve the capacity set out in paragraph 9.22, Commissioners may need to increase the level of home services available. For patients with advanced cancer, practical nursing care and support for extended periods may be provided by staff from a local hospice, the Marie Curie Nursing Service and others. In many cases, home nursing and hospice at home services may work closely together and some providers may offer both.

9.24 Mechanisms should be implemented to ensure that all patients who may benefit from specialist palliative care services have access to them at each stage in the patient pathway. To achieve this, the following measures should be taken:

- Cancer Networks should create a list of the locations and care capacity of all in-patient accommodation providing care for people with advanced cancer in the area, whether in hospitals, hospices, community hospitals or care homes
- all patients with advanced cancer should have their needs for palliative care assessed by a competent health care professional (see Topic 8, *General Palliative Care Services, including Care of Dying Patients*); the findings of this assessment should be shared with the specialist palliative care team, if appropriate
- service directories on supportive and palliative care should include information on specialist palliative care services and should be made available to all health and social care professionals and to patients and carers (see Topic 1, *Co-ordination of Care*)
- Cancer Network-wide referral guidelines and eligibility criteria should be developed and disseminated

- all specialist palliative care teams should work in close partnership with teams who refer patients to them; this might include participation in joint clinics (for example, with oncologists), multidisciplinary meetings and joint ward rounds
- teams should ensure that points of contact are clearly defined and widely known.

9.25 All specialist palliative care service providers within a Cancer Network should develop common approaches to the assessment, treatment and care of patients. This should lead to the publication and dissemination of guidelines, protocols and care pathways as appropriate, and will facilitate the delivery of high quality care and comparative audit.

### **Specialist multidisciplinary palliative care teams (in any setting)**

9.26 All multidisciplinary teams should be able to offer specialist advice, support and care for patients and carers. The service should be provided in conjunction with the GP and primary care team and specialties within a hospital, as relevant. The level of intervention will vary according to assessed needs, but will range from a purely advisory role to taking a lead in providing care. The team should also be able to provide advice and support to – and education and training for – professional colleagues.

9.27 To provide this level of specialist physical, psychological, social and spiritual care to patients and carers, specialist palliative care teams require:

- palliative medicine consultants
- palliative care nurse specialists
- a team secretary/administrator

and a range of expertise provided by:

- physiotherapists
- occupational therapists
- dietitians
- pharmacists
- social workers
- chaplains/spiritual care givers

- professionals able to deliver psychological support equivalent to Level 3 of the psychological support service model (see Topic 5, *Psychological Support Services*).

This expertise may be provided by named individuals on a full-time, part-time or regular sessional basis.

9.28 It is undesirable for a specialist palliative care team to be staffed by a single-handed medical consultant. Cross-cover arrangements may need to be developed where consultant cover is shared with neighbouring specialist teams or units. Currently, some teams are not led by a consultant holding a recognised appointment in palliative medicine. Local arrangements should be in place to provide specialist consultant input and advice to these services as an interim measure.

9.29 In addition to the personnel listed in 9.27, specialist palliative care teams should have access to the full portfolio of supportive care services, including:

- psychological support services (see Topic 5, *Psychological Support Services*)
- social support services (see Topic 6, *Social Support Services*)
- rehabilitation support services (see Topic 10, *Rehabilitation Services*)
- spiritual support services (often provided by a chaplain) (see Topic 7, *Spiritual Support Services*)
- input from site-specific cancer multidisciplinary teams
- services for families and carers (see Topic 12, *Services for Families and Carers, including Bereavement Care*)
- pain specialists with expertise in nerve blocking and neuromodulation techniques.

9.30 In many settings, specialists who are part of the 'extended' team also attend team meetings on a regular basis. This can be highly beneficial, and the team definitions set out above are not intended to diminish the impact of their involvement in any way.

- 9.31 Each multidisciplinary team should work to agreed Cancer Network guidelines or protocols. It should meet at least weekly and review the care of individual patients. Records, both of attendance and of patients discussed, should be maintained by the team secretary/administrator. The outcome of decisions on care should be recorded in the patient's notes<sup>T</sup>.
- 9.32 The team should be staffed to a level sufficient to undertake face-to-face assessments of all people with cancer at home or in hospital, 09.00-17.00, seven days a week. In addition, there should be access to telephone advice at all times (24 hours, seven days a week). This is considered a minimum level of service. Provision for bed-side consultations in exceptional cases outside the hours of 09.00-17.00, seven days a week is also desirable.
- 9.33 The team should have access to office space to enable the safe storage and efficient retrieval of records and information materials and to facilitate effective communication within and between teams.
- 9.34 Community specialist palliative care teams should develop good links with community hospitals and care homes and should ensure that staff in these settings have up-to-date information on how to access specialist palliative care services.

### **In-patient specialist palliative care services**

- 9.35 Commissioners should ensure that sufficient specialist palliative care beds (in hospices or hospitals) are available in each Cancer Network to meet the needs of the local population.
- 9.36 In-patient specialist palliative care facilities should be served by a specialist palliative care team (as described at 9.27), enhanced with nursing staff who have completed at least an introductory programme in the principles and practice of palliative care. Palliative medicine consultants should be supported by experienced medical staff so that medical cover can be provided on a 24-hours, seven days a week basis.
- 9.37 Around this core, the extended team should consist of a range of health and social care professionals to provide services, listed at 9.29. It is recognised that this full range of expertise may not be available within each in-patient facility. In this case, formal arrangements should be established with providers of neighbouring services to ensure access. Staff in these cases are likely to be members of several services simultaneously.

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<sup>T</sup> Help the Hospices is leading a programme of work – Hospice Connect – that aims to link all independent hospices in England to the NHSnet, so they may access and contribute to the electronic health record of the NHS Integrated Record Service.

- 9.38 Cancer Networks should establish guidelines setting out eligibility criteria for patients who warrant admission to specialist palliative care in-patient facilities.
- 9.39 In-patient specialist palliative care facilities should adhere to specifications set out in the Care Standards Act 2000<sup>4</sup>. While the Act does not specifically relate to the NHS, statutory providers should strive to ensure their facilities match its standards.

### **Specialist palliative care day therapy facilities**

- 9.40 Specialist palliative care day therapy facilities offer opportunities for assessment and review of patients' needs and enable the provision of a range of physical, psychological and social care interventions within the context of interaction, mutual support and friendship. A range of different types of services is already in existence, including provision of:
- medical care, such as blood transfusions and medication adjustment
  - nursing care, such as bathing and dressing changes
  - emotional and spiritual support
  - social support
  - services for families and carers.
- 9.41 Although many of these services can be provided on an individual basis elsewhere, specialist day therapy enables them to be brought together in one setting. It also brings patients together, providing social support and access to facilities, and can offer respite to carers. While research suggests that patients appreciate the social contact provided by day therapy, there is insufficient evidence to support the adoption of any particular model (or models). For example, interventions might be offered to patients during the course of attendance at a dedicated day facility or by appointment at a more formally arranged clinic (which might be located in a hospital, hospice or dedicated day therapy facility).
- 9.42 Commissioners, working through Cancer Networks and in partnership with existing providers of specialist palliative day care, should agree the objectives of local service provision and the types of interventions to be offered. This service might be delivered alongside other supportive care services such as complementary therapy and rehabilitation, and might have significant interaction with them. Account should be taken of other community-based services. The skills, expertise, activities and facilities necessary to support service delivery will depend upon the agreed functions of individual day therapy facilities.

- 9.43 Providers of specialist palliative day care should have mechanisms in place to ensure effective communication and co-ordination between different service elements, both specialist and general, involved in the care of individual patients.
- 9.44 As further evidence becomes available on access to day therapy, its acceptability and contribution to patients' quality of life and psychological and social well-being, service objectives should be reviewed.

### **C.3 Workforce development: specific recommendations**

- 9.45 Cancer Networks should assess their needs for each of the professional groups contributing to specialist palliative care teams as core and extended members. Workforce development should be planned in collaboration with Workforce Development Confederations in England and the Workforce Development Steering Group in Wales.
- 9.46 Specialist palliative care teams have a key role in delivering education and training to health and social care professionals providing generalist services. A Cancer Network-wide education and training plan should be developed, identifying priority staff groups. Specialist palliative care services should be sufficiently resourced to enable them to contribute to Cancer Network-wide education and training programmes.

### **C.4 Research and development: specific recommendations**

- 9.47 Research is needed to compare different models of palliative care services, covering issues such as skill mix, methods of working and mix of services (for example, between day care, home care, education and direct care). This should address their relative merits in different situations and for different patient groups.
- 9.48 Research is needed to determine cost-effective ways of providing specialist palliative care to patients and families outside the hours of 09.00-17.00, Monday-Friday.

## **D. Evidence**

### **D.1 The provision of services**

- 9.49 Studies and systematic reviews have demonstrated considerable benefit from adopting a multidisciplinary approach with specialist input [A]. This leads to a higher quality service than conventional care offered alone.



- 9.50 Reviews also show that specialist palliative care teams working in different locations, including homes, hospitals and in-patient units or hospices, improve outcomes for patients with cancer. This is independent of the composition of the team or the service.
- 9.51 There is no strong evidence to support a particular team composition in each setting, and no research evidence on the level of specialisation required for team members. Better outcomes tend to be observed, however, where teams are categorised as 'specialist' and consist of multidisciplinary trained staff, compared to those that have a nurse only or have had limited training. There is no evidence on the number of team members from each profession required to enable provision of an effective and efficient service.
- 9.52 Hospices and home care, compared to conventional care, have also been found to achieve similar or improved outcomes with respect to patient satisfaction, pain and symptom control and family anxiety.
- 9.53 No systematic reviews or randomised controlled trials on the effectiveness of specialist palliative day care services have been undertaken. A number of observational studies, however, offer information on their structure, process and outcomes for patients [B]. Surveys reveal a wide variety of models of care. Patients tend to report high levels of satisfaction, as day services provide social contact, some new activities and a chance to get out of the home; there is also some evidence of symptom control [B]. Studies have been hampered, however, by difficulties in evaluating an ongoing service and by the vulnerability of the patient population. The best model of care and most appropriate skill mix have not yet been determined. Issues of access also need to be addressed.

## **D.2 Organisation of care**

- 9.54 Given the complex nature of service provision, mechanisms for co-ordination and communication are needed to ensure appropriate and timely access to specialist palliative care services. Few studies have specifically examined continuity of care, but some have looked at aspects of care likely to improve as a result of achieving continuity. For instance, nurse co-ordinators appear to improve co-ordination between in-patient and home care teams, reducing the number of days spent by patients in hospital and the number of home visits [A].



- 9.55 The availability of a 24-hour telephone intervention (when combined with a specialist nurse co-ordinator, home care team linked with hospital, home care dossier and care protocols) has been shown to reduce re-hospitalisation, to improve patients' quality of life and to enable more patients to die at home [A]. Systematic reviews also suggest that specialist palliative care teams facilitate access to other services and co-ordinate care.

## E. Resource implications

- 9.56 The total cost of future specialist palliative care provision is estimated to be £440.3m for England and Wales. Total current expenditure is estimated to be £398.5m per annum. The incremental cost of guidance implementation is therefore approximately £42m.
- 9.57 The provision of specialist palliative care in-patient beds is the key contributor to the cost of services (£238m), followed by community specialist palliative care teams (£68m), hospital specialist palliative care support teams (£58m) and day care (£30m). Bereavement services, outpatient services and continuous support for dying patients account for £46m.
- 9.58 Costs presented include an element of double counting, given that the costs included with the specialist palliative care services estimates are also presented within individual topic areas (for instance, the cost of bereavement support services is also presented in Topic 12, *Services for Families and Carers, including Bereavement Care*).

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# 10. Rehabilitation Services

## A. Introduction

- 10.1 Cancer and its treatment can have a major impact on patients' ability to carry on with their usual daily routines. Activities that most people take for granted, such as moving, speaking, eating, drinking and engaging in sexual activity, can all be severely impaired. Treatment of cancer may involve amputation of a limb, removal of a breast or the creation of a stoma (an opening onto the body surface). The capacity of patients to care for themselves, to undertake day-to-day activities, to work and to pursue their previous interests may all be affected.
- 10.2 Cancer rehabilitation attempts to maximise patients' ability to function, to promote their independence and to help them to adapt to their condition<sup>1</sup>. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individual's physical, psychosocial and economic functioning. The importance of rehabilitation services in improving patients' lives is gaining more recognition and they are increasingly being seen as integral to patient care.
- 10.3 Although rehabilitative interventions are often considered primarily in terms of their physical impact for patients, they can also have major psychological, social and spiritual benefits.
- 10.4 Services are provided by a range of allied health professionals (AHPs) and other professionals, including:
- appliance officers
  - dietitians
  - lymphoedema therapists
  - occupational therapists
  - oral health specialists such as dental hygienists
  - physiotherapists
  - psychosexual counsellors

- speech and language therapists
- stoma therapists
- therapy radiographers.

- 10.5 Rehabilitation is not solely the responsibility of professionals with specialist rehabilitation expertise. All health and social care professionals can play a part, as patients may benefit from efforts to promote their well-being whatever their stage of illness and wherever care is being provided. Patients can also play a central role in their own rehabilitation, and many take an active role through self-management.
- 10.6 While patients' needs will differ, all patients are likely to need rehabilitation at some stage in the patient pathway. Problems with mobility, function and daily activities arising from cancer and its treatment can contribute to feelings of loss of control, compromising well-being and affecting feelings of self-worth. Problems can persist long after treatment has concluded; access to rehabilitative services for patients in long-term remission or those whose cancer has been cured needs to be considered alongside patients in active treatment, in advancing disease or those requiring support at the end of life.
- 10.7 Expressing sexuality remains important to many people with cancer, regardless of age, and can be fundamentally compromised by the condition and its treatment. Cancer has an impact on intimate relationships, can cause specific sexual dysfunction, and affects how people perceive their sexual identity through, for example, a changed body image. Because sexuality is an issue that many people – health and social care professionals and patients – find difficult to address, there can be a failure to offer or seek information and support.
- 10.8 The needs for rehabilitation among some groups have traditionally been more readily recognised than others – patients with cancer of the head and neck and those with bone tumours, for instance. Rehabilitative approaches are just beginning to evolve for other groups, such as people whose disease is progressively deteriorating or those in clinical remission following arduous treatment.
- 10.9 There are currently few integrated multidisciplinary teams that include professionals with particular rehabilitation expertise in the areas of cancer and palliative care. Exceptional examples can be found, however, with some providers developing rehabilitation units or services that include nurses, doctors, physiotherapists, occupational therapists, dietitians, speech and language therapists, lymphoedema therapists and oral health specialists.

- 10.10 There are currently no clearly defined career pathways linked to post-registration education and training programmes for AHPs wishing to develop their clinical expertise in cancer care. The establishment of such programmes would enhance the knowledge and skills of practitioners at all levels and would encourage movement into specialist posts at a higher level.
- 10.11 No formal evaluation of rehabilitation services for cancer patients has been undertaken nationally. There is nevertheless widespread consensus among practitioners and patients that patients do not always receive the rehabilitation services they need, for several reasons:
- front-line practitioners frequently do not recognise patients' needs for rehabilitation and may be unaware of the benefits that could be derived from assessment and intervention by a skilled AHP
  - availability of AHPs may be limited
  - AHPs may be inadequately trained in dealing with problems faced by people with cancer in specific situations
  - delays in accessing equipment and facilities may occur with failure to prioritise services required, particularly for patients at the end of life.

## B. Objectives

- 10.12 The objectives are to ensure that:
- all patients have their needs for rehabilitation services assessed throughout the patient pathway, with particular attention given to points recognised as being especially challenging for patients and carers (such as at the time of diagnosis and early treatment planning, the end of treatment, recurrence, preparation for discharge after in-patient admission, and towards the end of life)
  - patients receive an active and planned approach to rehabilitation that involves assessment, goal setting, care planning and evaluation and, for patients who might benefit, timely referral to rehabilitation specialists
  - all patients who need rehabilitation services access them when and where they need them, and services are provided without undue delay

- an education and training programme is available to staff involved in the recognition and provision of rehabilitation services for patients with cancer.

## C. Recommendations

### C.1 Overview

- 10.13 The rehabilitation needs of patients should be assessed at key points in the patient pathway, using an assessment tool agreed across the Cancer Network.
- 10.14 Rehabilitation services should be organised to ensure that a range of expertise is available within a Cancer Network and close working relationships with site-specific multidisciplinary teams, specialist palliative care and primary care teams are fostered.
- 10.15 Access to AHPs should be clearly defined at each stage of the patient pathway through referral and treatment criteria, including self-referral routes of access.
- 10.16 Education and training programmes should be provided to enable defined levels of input to be achieved.
- 10.17 All specialist rehabilitation service providers within a Cancer Network should develop and implement evidence-based guidelines against which practice can be audited.

### C.2 Service configuration and delivery: specific recommendations<sup>U</sup>

- 10.18 Commissioners, working through Cancer Networks, should ensure they can provide the range and volume of rehabilitation services appropriate to meet the needs of the local population. This will include providing services from the following:
- appliance officers
  - dietitians
  - lymphoedema therapists

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<sup>U</sup> The first national allied health professional cancer strategy will be published in 2004, covering recruitment, retention, education, training and professional development. Those involved in providing specialist advice to the guidance development team on this topic (see Appendix 2.5) have also been involved in the development of the strategy. Implementation of the strategy will be critical to the implementation of these recommendations.

- occupational therapists
- oral health specialists such as dental hygienists
- physiotherapists
- psychosexual counsellors
- speech and language therapists
- stoma therapists
- therapy radiographers.

10.19 Commissioners, working through Cancer Networks, should ensure that patients with rehabilitation needs are identified and can access an appropriate level of rehabilitative support. This might involve the use of a Cancer Network-wide assessment tool to ensure that functional needs likely to benefit from rehabilitative interventions are recognised. The assessment tool should be used in all care settings, including the community, and should include assessment of the following:

- nutritional status
- mobility
- self-care, including dressing and personal hygiene
- oral health
- coping at home
- work and leisure activities.

10.20 Each Cancer Network should identify a lead advanced practitioner AHP to work with the Network management team. Cancer Networks should also identify a lead for each of the main therapy groups to work with the lead advanced practitioner AHP. These individuals will lead a programme of work that should include:

- developing and implementing a Cancer Network-wide strategy to ensure patients' rehabilitation needs are recognised and met through the use of a Cancer Network-wide assessment tool

- establishing referral and treatment criteria to ensure needs are met at the appropriate level of expertise: these should include strategies generalist health care professionals can initiate and contact details for identified specialists to whom patients can be referred (or can access through self-referral processes in specific circumstances)
- identifying target times for access to services, equipment and facilities in all care settings
- overseeing the provision of specialist input across the Cancer Network
- agreeing an education and training programme to meet the levels of rehabilitation interventions required, and contributing to this programme
- auditing aspects of Cancer Network rehabilitation services, including quality, access and timeliness.

10.21 Commissioners should ensure a comprehensive rehabilitation service is available in all care settings 09.00-17.00, Monday-Friday. Once the need for referral to a specialist rehabilitation service is identified and a referral made, it should be provided within specified target times.

10.22 Within each care setting, a model for assessing and meeting rehabilitation needs should be developed and implemented (a recommended model is shown in Figure 10.1). This should include the use of a Cancer Network-wide assessment tool and criteria for referral and treatment, and should be integrated with other assessment processes. Patients should be assessed at key points in the patient pathway, such as at the end of treatment and towards the end of life, and when circumstances change.

**Figure 10.1**

<b>Recommended model of rehabilitation assessment and support</b>				
<b>Level</b>	<b>Patient need (examples)</b>	<b>Group providing input</b>	<b>Assessment</b>	<b>Intervention</b>
<b>1</b>	<ul style="list-style-type: none"> <li>• Simple energy conservation techniques</li> <li>• Simple or first-line dietary advice</li> <li>• Advice to patients regarding skin care and risks of developing lymphoedema</li> </ul>	<ul style="list-style-type: none"> <li>• Patients and carers' assessment</li> <li>• General nursing staff</li> <li>• Therapy radiographers</li> <li>• Assistant practitioners/ support workers</li> </ul>	Recognition of needs for help and support based on assessment of function	Basic interventions, including self - management, and care strategies initiated by generalist health care professionals
<b>2</b>	<ul style="list-style-type: none"> <li>• Post-operative physiotherapy following breast surgery</li> <li>• Dietary advice for patients having enteral feeding regime</li> </ul>	Generalist AHPs	Routine assessment of rehabilitation needs	Interventions provided for commonly presenting rehabilitation needs - post-operative input plus management of commonly presenting side-effects of treatment or functional impairment
<b>3</b>	<ul style="list-style-type: none"> <li>• Post-operative physiotherapy following breast surgery</li> <li>• Dietary advice for patients having enteral feeding regime</li> </ul>	Experienced AHPs with basic level training in cancer rehabilitation working at senior level	Specialist assessment from an experienced AHP	Interventions provided by professionals with knowledge and experience of effects of cancer treatment and aetiology; interventions requiring knowledge of the impact of disease
<b>4</b>	<ul style="list-style-type: none"> <li>• Management of a patient with spinal cord compression</li> <li>• Swallowing assessment for patient having had radical head and neck surgery</li> <li>• Management of severe/complicated lymphoedema</li> </ul>	Advanced practitioner AHPs working predominantly or exclusively with patients with cancer and with higher-level training as specialist practitioners	Highly specialist assessment from expert AHP	Highly specialist interventions for patients having radical surgery, patients with advanced disease, patients with severe functional impairment, patients undergoing combination therapies and/or patients with complex end of life issues



10.23 Referral pathways between and to each level should be established, including the ability of the patient and carer to self-refer.

10.24 Those involved at each level and their functions are as follows:

**Level 1** involves all those providing day-to-day care for a patient, including the patient and carer. Patients' needs are assessed using an agreed assessment tool, with basic interventions initiated or a referral made to the next appropriate level of care.

**Level 2** involves all generalist AHPs. Patients' rehabilitation needs may be provided by the appropriate AHP at this level, cross-referring to AHP colleagues as necessary, or patients may be referred to a more experienced colleague, according to need.

**Level 3** involves experienced AHPs with basic-level training in approaches to managing cancer. These professionals may work across a care setting, such as a Primary Care Organisation or acute NHS Trust, and will also cross-refer as necessary, delivering interventions requiring knowledge of the impact of the disease and its treatment.

**Level 4** involves advanced practitioner AHPs who work predominantly or exclusively with patients with cancer and who provide expert advice and input for clearly defined rehabilitation needs. These expert AHPs will have received higher-level training in the rehabilitation needs of patients with cancer.

10.25 Health care professionals other than AHPs may play a role at Levels 2, 3 and 4. For example, some nurse specialists, having undergone training, may assess and manage lymphoedema and breathlessness.

10.26 The outcome of the assessment process at all levels should be a set of individual goals recorded in the patient's clinical notes and used as the basis for a care plan. Patients should play a central role in setting these goals and in subsequent assessments to identify changing need. Where rehabilitation needs are identified that cannot be met in a patient's current setting due to a lack of skills, facilities, or both, onward referral to specialist rehabilitation therapists or facilities should be made.

- 10.27 Patients coming to the end of treatment should continue to have access to rehabilitative therapies for an indefinite period, and should know how to initiate such access. In the first instance, this is likely to be through their 'key worker' (see Topic 1, *Co-ordination of Care*). Teams should ensure such patients are given opportunities to prepare for their life after treatment through support and advice on employment, financial difficulties and personal relationships (see Topic 5, *Psychological Support Services*). Such support might take many forms, including support and self-help groups, peer-to-peer support, and consultations with health and social care professionals with the necessary expertise.
- 10.28 Providers should have mechanisms in place for patients to access user-led self-management programmes (in England, these should be in line with the Expert Patient Programme<sup>2</sup>). These should ideally be developed in partnership with patients' organisations.
- 10.29 Site-specific and specialist palliative care teams in hospitals, hospices and primary care should form close working relationships with rehabilitation professionals, based on this framework, to ensure that patients' needs are recognised and referral pathways used. AHPs should be part of site-specific multidisciplinary team meetings as appropriate; for example, a speech and language therapist might participate in a head and neck cancer team meeting, or a dietitian might participate in an upper GI team meeting.
- 10.30 Providers should ensure suitable facilities and ready access to equipment to support effective and safe rehabilitation. They should ensure equipment is available to enable patients to continue their rehabilitation plan at home. Priority should be given to those patients who are dying. Equipment required by a patient approaching the end of life should be made available within 24 hours of the request.
- 10.31 Providers should be able to demonstrate robust systems of forward planning for orders and delivery times, with capacity to anticipate individual patient needs for appliances such as appropriate wigs, stoma bags, lymphoedema hosiery and prostheses. A ready supply of appliances commonly needed by patients with particular conditions should be available. Patients should be made aware of the appropriate person to contact to obtain fresh supplies or to discuss problems or concerns.

- 10.32 Providers should ensure designated facilities are available for demonstrations and fitting of appliances, with sufficient space for these activities to be carried out effectively. Such facilities should confer privacy and be stocked with items such as mirrors, a couch, washbasin and storage cupboards.
- 10.33 Providers should ensure appliances are fitted by skilled individuals who have an appreciation of the needs of patients with cancer and are knowledgeable about the relevant appliance.
- 10.34 Providers should ensure their rehabilitation team has individuals with the necessary skills to offer support to enable people to resume their usual sexual practices or explore alternative ways of achieving sexual fulfilment.

### **C.3 Workforce development: specific recommendations**

- 10.35 Workforce Development Confederations (the Workforce Development Steering Group in Wales), working with Cancer Networks, should assess the level of need for training and commission sufficient training places to meet the following requirements:
- all health care professionals should receive training in rehabilitation needs assessment
  - a foundation course in approaches to cancer management should be established and provided for all experienced AHPs working at Level 3
  - higher-level education should be established and provided for all advanced practitioner AHPs working at Level 4.
- 10.36 A 'cascade' model of training might be an effective way to ensure that rehabilitation experts play a key role in disseminating knowledge and skills across a Cancer Network. Advanced practitioners should have sufficient time rostered within their job plans to enable these activities to be undertaken.
- 10.37 'Clinical specialist' and 'consultant therapist' posts in cancer and palliative care should be developed across all AHP groups to ensure patient access to practitioners necessary to deliver high quality rehabilitation services. The total number and skill-mix of AHP staff needed to support service delivery should also be reviewed.

## **C.4 Research and development: specific recommendations**

- 10.38 Research is needed to explore the role, components and outcomes of rehabilitation, including the contribution of AHPs.
- 10.39 Research is needed to determine what models of rehabilitation are most effective for different patient groups and how these are best integrated with other services.

## **D. Evidence**

- 10.40 A number of individual studies have been undertaken on the effectiveness of various interventions to provide rehabilitation for patients with cancer. These have investigated the impact of interventions at different stages in patients' experience of cancer (initial diagnosis, treatment, recurrence, end of life) and with patients with different forms of cancer. Most studies are American, with little UK research in this area. No systematic reviews have been undertaken.
- 10.41 A small amount of research has focused on the functional recovery of hospital in-patients as a result of rehabilitation. Two studies found that patients with a wide variety of cancers made significant gains in motor function and, in one, most patients also made significant gains in cognitive function<sup>3,4</sup> [B].
- 10.42 Education interventions have generally proved successful. Research suggests that a general training programme providing information on physical exercise and coping skills can improve the physical and emotional well-being of patients [A]. Similarly, specific training programmes on, for instance, helping people with cancer-related fatigue or breathlessness can result in significant improvements in functioning [A]. Two studies of the impact of an intervention to provide walking exercise for patients with cancer receiving adjuvant chemotherapy and radiotherapy respectively found that this improved their physical functioning and lowered their levels of fatigue and emotional distress [A]. A programme to assist compliance with vaginal dilation among women with gynaecological cancer was found to be effective in increasing compliance and reducing fears about sex after cancer [A].
- 10.43 Research also demonstrates that self-administered stress management training for patients about to start chemotherapy is particularly effective, at a much lower cost than professionally administered interventions [A]. Employing a self-help approach seems to bring positive outcomes in terms of self care, psychological adjustment and confidence in cancer knowledge, regardless of baseline resourcefulness [A]. Input from a dietitian to avoid unwanted weight gain among women

receiving adjuvant chemotherapy produced small but statistically insignificant reductions in both calorie consumption and weight gain [A].

- 10.44 There is growing evidence to show that, compared to no intervention ('standard care'), self-management approaches can provide important benefits for participants. These include reduced severity of symptoms, significant decreases in pain, improved life control and improved resourcefulness and life satisfaction<sup>5-8</sup> [B]. Macmillan Cancer Relief, through its *Living With Cancer* project, is exploring the outcomes of different models of self-management: a lay-led programme aimed at developing people's abilities in problem solving and self-care, and a professionally-led programme aimed at developing people's knowledge of the illness<sup>9</sup>.
- 10.45 Interventions involving combined approaches have also generally been found to be successful. These include a programme within primary care to increase contacts with home care nurses, including individual psychological support and, for some, help from a dietitian, which found that the intervention was the strongest predictor of patients' contact with home care nurses six months after diagnosis [B]. Another intervention for patients with breast cancer, involving a team who provided support after surgery which included an oncology counsellor to provide support and information and a social worker to co-ordinate arrangements between hospital and the community, resulted in the expression of more emotional problems immediately and a greater sense of self-efficacy two months later [B]. A comprehensive intervention for women with breast cancer suffering from menopausal symptoms, consisting of a structured assessment followed by an individualised plan of education, counselling, pharmacological and behavioural interventions, support and referrals, was found to result in improvements in symptom management and sexual functioning [A].
- 10.46 There has been little research on patients' views of rehabilitation, but one study found patients cared for on a rehabilitation ward specifically focusing on people with cancer welcomed direct help with their condition and support gained from other patients; they also felt more involved in their own rehabilitation as a result<sup>10</sup> [B]. A study of patients with breast and bowel cancer found only one quarter, generally those with physical or psychological problems, expressed an interest in having professional rehabilitation following treatment. Focus groups and interviews elicited that the kinds of help sought included information on the disease, diet and how to cope better in their new circumstances<sup>11</sup> [B].

- 10.47 One study of the appropriateness of professional assessments for rehabilitation suggests a lack of clear referral criteria among nurses<sup>12</sup> [B]. There is evidence that education and training of those who are not specialists in this field is likely to result in better recognition of patients' rehabilitation needs and a greater appreciation of the wider multidisciplinary team. An education intervention for professionals proved to be effective for people from a wide range of health care disciplines (oncologists, nurses, mental health professionals), improving their knowledge of cancer pain, psychosocial issues and rehabilitation issues [B].
- 10.48 Interventions for cancer rehabilitation tend to be multi-faceted to address the often complex adverse physical and psychological effects of cancer and to promote adaptation to treatment. The importance of multidisciplinary teamwork is a common theme in professional guidance on this subject<sup>13,14</sup> [C]. More research is needed to investigate the particular impact of different interventions for patients with different types of cancer and at different stages.

## E. Resource implications

- 10.49 The estimated cost of implementing the four-level model of rehabilitation assessment and support recommended in the Guidance is estimated to be £23.8m. This is the full cost, assuming no current service provision. Of this, approximately one third is assumed to be within specialist palliative care and two thirds within supportive and general palliative care. The current cost of rehabilitation services is not known, meaning the incremental cost of the Guidance over and above the current cost is not known. Staffing assumptions and resultant cost estimates are considered to be a minimum requirement that should be achieved by all Cancer Networks.
- 10.50 Education and training requirements include training in rehabilitation needs assessment for health care professionals and education of AHPs in the basics of cancer rehabilitation.

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# 11. Complementary Therapy Services

## A. Introduction

- 11.1 Making decisions on the appropriate provision of complementary therapy services for patients with cancer is difficult. A considerable proportion of patients express interest in the use of complementary therapies and a significant number report they have used complementary therapies for their condition. Yet there is little conventional evidence on the effectiveness of these therapies for the relief of pain, anxiety or distress, or for improving quality of life. In addition, some complementary therapies may present risks to patients, as well as benefits.
- 11.2 Against this background, the aim is to provide guidance that will:
- enable patients to obtain reliable information about complementary therapies and therapists, to empower them to make decisions for themselves
  - assist commissioners in determining what, if any, complementary therapy services they should fund
  - give advice to providers on the measures they should take to ensure patients can access complementary therapies safely, should they so wish.
- 11.3 This Guidance does not attempt to make recommendations regarding individual complementary therapies, just as specific recommendations have not been made for conventional treatments in other topic areas.
- 11.4 *Complementary* therapies are used alongside orthodox treatments with the aim of providing psychological and emotional support through the relief of symptoms. *Alternative* therapies purport to offer a distinct alternative to orthodox cancer treatments, and are not considered in this Guidance.



- 11.5 Complementary therapies encompass a diverse range of interventions, including physical, psychological and pharmacological therapies. Therapies may be considered as self-care approaches (meditation, for instance), as techniques (massage) or as interventions with a range of clinical applications (homeopathy). All are used in this context in addition to, rather than in place of, orthodox cancer treatments to help with symptom control and to enhance general well-being. The most widely used by patients with cancer are the touch therapies (aromatherapy, reflexology and massage) and psychological interventions (relaxation, meditation and visualisation)<sup>1</sup>.
- 11.6 Patients with cancer may access complementary therapy services from a variety of sources in the statutory, voluntary and independent sectors. They are delivered in settings such as general practices, hospitals, hospices and diverse community locations, including self-help and support groups.
- 11.7 Recent reports in the UK have indicated that between 9% and 30% of patients with cancer have used complementary or alternative therapies for their condition<sup>2,3</sup>. Many NHS and voluntary sector organisations offer complementary therapy services<sup>4</sup>. Attitudes of doctors, nurses and allied health professionals have changed considerably over the last ten years, from a position of scepticism and frank antagonism in some cases, to a productive co-existence<sup>5</sup>.
- 11.8 Under UK common law, no formal training is required to practice most forms of complementary therapy (with the exception of osteopathy and chiropractic, whose practitioners achieve registration in a similar way to medical practitioners, dentists, allied health professionals and nurses). Recommendations have been made for the statutory regulation of acupuncture and herbal medicine, with the government expected to produce a document for consultation in the near future. Work is in hand to strengthen the voluntary regulation of aromatherapy, homeopathy, massage, reflexology and others, based on the adoption of national occupational standards.
- 11.9 Some NHS organisations have developed policies on qualifications, professional registration and indemnity in relation to complementary therapies. These are not unique to cancer services. It is widely acknowledged that issues relating to training, qualifications and competence should be addressed at national level to ensure safety for patients.

## B. Objectives

11.10 The objectives are to ensure that:

- patients are empowered to make their own decisions about complementary therapies and therapists through the provision of high quality information
- complementary therapies either commissioned by the NHS or provided in NHS facilities are provided safely by trained practitioners who are sufficiently aware of clinical problems and psychological issues with which patients with cancer can present.

## C. Recommendations

11.11 Commissioners, NHS and voluntary sector providers and user groups 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. The Cancer Network may choose to establish some form of complementary therapy interest group to:

- review evidence related to best practice<sup>VW</sup>
- agree policies to ensure safe practice
- develop complementary therapy components of a service directory.

11.12 Commissioners should determine what complementary therapy services they wish to fund and in what setting and whether these should be made available for particular groups of patients, ensuring equal access for all patients meeting the relevant criteria. They should take account of the views of patients and health and social care professionals in determining local provision.

11.13 Provider organisations should ensure patients have access to high quality information about complementary therapy services and where they can be obtained<sup>X</sup>.

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<sup>V</sup> An evidence-based information resource in complementary medicine is currently under development by the Research Council for Complementary Medicine (with a specific section devoted to cancer).

<sup>W</sup> Cancer Networks might wish to consider the national guidelines for use of complementary therapies in palliative care developed by the National Council for Hospice and Specialist Palliative Care Services and the Prince of Wales Foundation for Integrated Health<sup>6</sup>.

<sup>X</sup> The Department of Health has commissioned the Prince of Wales Foundation to provide a guide for patients. This should be available shortly.

- 11.14 Provider organisations should ensure patients have access to a knowledgeable individual with whom they can discuss complementary therapies.
- 11.15 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.
- 11.16 Provider organisations should ensure facilities are made available for the delivery of those forms of complementary therapy that have been agreed at Cancer Network level.
- 11.17 Those involved with the provision of therapies within the context of the NHS should make every effort to contribute to their ongoing evaluation, participating in research designed to establish their efficacy and impact.

### **Research and development: specific recommendations**

- 11.18 Evaluative research is needed into the cost effectiveness and safety of different complementary therapies in supportive and palliative care.
- 11.19 Research is needed to determine the best ways to deliver and provide information about complementary therapy services.

## **D. Evidence**

- 11.20 In common with many non-pharmacological clinical interventions, the evidence base for the effectiveness of complementary therapies does not offer the same level of assurance secured for interventions supported by numerous well-conducted randomised controlled trials that have subsequently had favourable systematic reviews.
- 11.21 Such reviews that exist are mentioned in the Evidence Review. It should be noted, however, that in a report published in November 2000, the House of Lords Select Committee on Complementary and Alternative Therapies recommended that therapies which claim to relieve, rather than cure, certain conditions should be subject to less stringent standards of evidence<sup>7</sup>. While the evidence is not as rigorous as might be desired, there is a body of evidence on the effectiveness of complementary therapies in cancer care currently being assembled by the Research Council for Complementary Medicine (RCCM). Until this work is completed, the fact that these therapies are already in wide and effective use in the NHS and voluntary sector may be taken as a significant indication of their value.

- 11.22 Studies suggest that up to one-third of patients with cancer in the UK may visit therapists<sup>2,8</sup>, most commonly for touch therapies (aromatherapy, massage, reflexology), mind-body therapies (relaxation and visualisation) or healing and energy work (reiki, spiritual healing, therapeutic touch)<sup>9</sup> [B]. Many more take remedies or use other products [B]. Use of such therapies also appears to be increasing, with most patients using complementary therapies alongside conventional medicine rather than as a distinct alternative [B]. Patients have been found to be very satisfied with such treatments [B].
- 11.23 Patients with cancer use complementary therapies because they feel the remedies are non-toxic and holistic, allow them more participation in their treatment and involve supportive relationships with practitioners [B]. They also see complementary therapy as a means of improving their quality of life and controlling symptoms of cancer or cancer treatments [B]. Users tend to be women, are on average younger and come from higher socio-economic backgrounds than non-users [B].
- 11.24 Although much complementary therapy is provided privately or through voluntary organisations, its provision within the NHS is growing. Many hospices and oncology departments in the UK offer at least one complementary therapy to patients, with over 50% of services offering more than five therapies<sup>4</sup>. Almost half of GPs in England provide access to some form of complementary therapy<sup>10</sup>, and two-thirds of oncology departments claim to provide therapies<sup>11</sup> [B].
- 11.25 The evidence review to accompany the development of the recommendations has largely been confined to systematic and non-systematic reviews. These demonstrate that evidence on the effectiveness of complementary therapies is limited, with most therapies not having rigorous evaluations. One Cochrane review, however, suggests that aromatherapy and/or massage confer short-term benefits for patients with cancer in terms of psychological well-being and, probably, a reduction in anxiety and some physical symptoms<sup>12</sup> [A]. Another found positive benefits for patients with cancer from reflexology in breathing, reduction in anxiety and reduced pain<sup>13</sup> [A].
- 11.26 There have been three systematic reviews of randomised controlled trials and studies of other complementary therapies, not limited exclusively to patients with cancer. Two provide some evidence of the benefits of aromatherapy in reducing anxiety [A] and acupuncture in reducing nausea and vomiting [A]. Preliminary results of a systematic review

of chemotherapy-related nausea and vomiting is also positive for acupuncture<sup>14</sup> [A]. There is some indication that therapies might have the ability to improve patients' general sense of well-being and quality of life through, for instance, reductions in distress, anxiety, pain and nausea [B].

- 11.27 Many studies have a considerable number of methodological limitations, making it difficult to draw definitive conclusions. The best research, where it exists, offers some support for the use of certain complementary therapies in cancer care, but the same cannot be said for claims that complementary therapies cure cancer. A few determined patients have found remission after following a very strict unorthodox regime, but there is no reliable evidence that these results are generally reproducible.
- 11.28 The Department of Health has recently commissioned research that explores perceptions, preferences, expectations and outcomes about complementary and alternative medicine treatments in patients with cancer<sup>15</sup>.

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# 12. Services for Families and Carers, including Bereavement Care

## A. Introduction

- 12.1 Cancer affects the whole family and significant adaptation is necessary when one member becomes ill. While the needs of family members and other carers have to some degree been addressed within the other topics of this Guidance, this topic area focuses on their specific needs and the services required to support them.
- 12.2 A broad definition of ‘family’ is used, including those related through committed heterosexual or same sex partnerships, birth and adoption, and others who have strong emotional and social bonds with a patient. Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management<sup>1</sup>.
- 12.3 Families and carers provide crucial support for patients, yet their importance can go unrecognised by professionals. Close family members usually try to keep things going on a normal basis within the family, consequently remaining ‘invisible’ to health and social care professionals. Because families and carers often put the needs of the patient first, it is difficult to get them to express their own needs, which may be different from those of the patient. Care-giving may not necessarily be viewed as ‘burdensome’ by family members; it has both positive rewards and negative elements. It is recognised, however, that for a variety of reasons, not every family member will be able – or will choose – to adopt a caring role.
- 12.4 Family and carers can struggle to cope with watching their loved one suffer from the symptoms of cancer and its treatment. Multiple issues come into play, including emotional strain, the physical demands of caring, uncertainty, fear, altered roles and lifestyles and matters of personal and sexual intimacy. While their emotional distress can be greater than that experienced by the patient, family members have fewer



opportunities to express their feelings. This distress can manifest in a number of ways, including fatigue, weight loss, insomnia and vulnerability to infection.

- 12.5 Information and support needs will differ at discrete points in the patient pathway, with crucial times identified as the point of diagnosis, the end of first treatment, disease recurrence and the terminal phase. Practical needs revolve around help with transport, maintaining the home and caring for any other dependents, financial matters, coping with distressing symptoms and dealing with the tiredness that accompanies caring. Help may also be needed in dealing with their own and others' feelings. Difficulties can arise if their choices and judgements are at variance with those of the patient or others in the same family group, raising the possibility of conflict and creating ethical dilemmas for professionals.
- 12.6 Families and carers have particular needs around the time of death that may only be fully realised after the patient's death. Grief is a normal response to human loss, and while bereavement represents a significant challenge, the majority of people have sufficient resources to enable them to respond and adapt to this life transition. Most find a way of adjusting to the loss, but some may find it too difficult or traumatic without additional support.
- 12.7 Bereavement can give rise to a wide range of needs – practical, financial, social, emotional and spiritual. There might be needs for information about loss and grief, needs to pursue particular cultural practices, needs for additional support to deal with the emotional and psychological impact of loss by death or, in a small number of circumstances, specific needs for mental health service intervention to cope with a mental health problem related to loss by death.
- 12.8 Services for families and carers are poorly developed in many parts of England and Wales, although the situation is somewhat better in relation to specialist palliative care. While policy initiatives have been developed<sup>Y</sup>, service delivery is fragmented and is commonly targeted at discrete groups, with much being funded by the voluntary sector. Sources of help, support, information and advice may be both insufficient and inappropriate. Many family members and carers have virtually no contact with professionals, leading to professionals making erroneous assumptions about their coping and often leaving families and carers unaware of additional resources, services or sources of support.

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<sup>Y</sup> Cancer Networks should appraise themselves of the Department of Health<sup>2</sup> and Welsh Assembly Government<sup>3</sup> strategies on caring for carers.



- 12.9 Different forms of support are available for those experiencing bereavement, ranging from information, through befriending and self-help groups, to more formalised psychological interventions such as counselling. These are provided by the statutory and voluntary sectors, with voluntary services often providing the lion's share.
- 12.10 Inequitable distribution of bereavement services and their varying quality are ongoing concerns. Families and carers, particularly of patients who are not receiving specialist palliative care, may never undergo screening to assess their level of vulnerability. They may consequently experience delays in receiving additional support, or may not receive support at all. Professionals are often not adept at assessing, predicting and responding to families' and carers' bereavement needs, both before and after death.
- 12.11 Professionals need to pay greater attention to the role played by carers and their psychological and social needs. Carers, however, tend to put the needs and interests of patients above their own. They will only be likely to accept services designed to support them if they are confident that in doing so, they are not diverting resources and attention away from services to the patient.

## B. Objectives

12.12 The objectives are to ensure that:

- family members' and carers' needs are assessed, acknowledged and addressed
- carers have access to levels of practical and emotional support sufficient to enable them to fulfil the role of carer
- those who experience bereavement receive support to facilitate grieving, to prevent the detrimental consequences of bereavement
- health and social care workers can access support to enable them to come to terms with loss and bereavement issues they encounter in their work.

## C. Recommendations

### C.1 Overview

- 12.13 Family members and carers should be offered the opportunity for their needs for support and information to be assessed separately from those of patients, particularly at stages in the patient pathway acknowledged as especially demanding and when extra help might be needed. Cultural and ethnic preferences on family involvement should be taken into account.
- 12.14 Whenever possible and appropriate, family members and carers should be invited to accompany patients during clinical encounters and should be involved in discussions about treatment and care, in accordance with the patient's wishes.
- 12.15 Family members and carers should be made aware of, and have easy access to, sources of local information, advice and support designed to meet their own needs.
- 12.16 Family members and carers who are bereaved should, in the first instance, be encouraged to use existing support systems. Where these prove insufficient, or it is predicted that those involved are likely to experience difficult grief reactions, there should be access to additional help and support.
- 12.17 Providers of specialist bereavement support should work closely with other care providers (both statutory and voluntary) to ensure carers and family members can access services when needed.

### C.2 Service configuration and delivery: specific recommendations

- 12.18 Commissioners, working through Cancer Networks, should ensure that a range of information, support (including practical help and respite arrangements) and bereavement services are in place to meet the spectrum of need. They will need to work with statutory and voluntary health and social care agencies to achieve this. While not necessarily separate from many of the services provided to patients (indeed, most will be fully integrated), commissioners should ensure sufficient capacity to meet the distinct needs of this group.
- 12.19 Provider organisations should nominate a lead to oversee the development and implementation of services that specifically focus on the needs of families and carers. This role might involve:
- leading on the development of criteria and routes of referral to sources of specialist support and advice

- appraising written information currently provided to families and carers and, in conjunction with the NHS Trust information lead, developing further resources where necessary
- regularly appraising sources of local and national support for families and carers
- acting as a resource for teams considering the development of programmes of support for families and carers.

12.20 Health and social care professionals providing day-to-day care to patients should assess and address the needs of family members and carers on an ongoing basis. Teams should establish a system to ensure family members and carers have regular opportunities to discuss particular concerns. This might be achieved by offering them an appointment with the 'key worker' (see Topic 1, *Co-ordination of Care*) at times acknowledged to be particularly challenging (diagnosis, end of treatment, recurrence, palliation, time of death).

12.21 Where carers are providing a substantial amount of care on a regular basis, providers should ensure they are offered a separate assessment or respond positively when a carer asks for one, in accordance with The Carers (Recognition and Services) Act 1995<sup>4</sup>. The practice guide that accompanies the Act recommends potential areas to be covered in an assessment to identify the types of support needed, which can then be used to plan timely and relevant interventions.

12.22 Teams should ensure that all family members and carers are offered information on a variety of topics, from a simple 'who's who' of professionals to more detailed accounts of cancer, its treatment and consequences and services available locally. They should be 'signposted' to local and national sources of information, advice and practical support, including sources of emotional and psychological support. Services for carers and families should be listed in the directories developed at Cancer Network level.

12.23 Teams should provide families and carers with a clear indication of the personnel they might contact in relation to a range of needs.

12.24 If they wish, patients with young children or teenagers should be offered information by the health and social care professionals providing day-to-day care on how to encourage the sharing of fears and concerns. Age-appropriate resources should be available to support this process (see Topic 4, *Information*).

- 12.25 Providers should set up arrangements for families and carers to meet other families and carers who have experienced similar situations, if wished. Support groups for family members and carers, either professionally or peer-led, may also be welcomed by some. These services are ideally provided in partnership with the voluntary sector.
- 12.26 Awareness of the needs of family members from different ethnic populations, including differences in language, religious practice and culture, is necessary within a multi-cultural society. Providers should ensure teams have access to reference guides on the cultural differences surrounding a diagnosis of cancer, death and dying, and that information on accessing interpreters, relevant health advocates (where available) and faith leaders is readily accessible (see Topic 3, *Face-to-Face Communication*, and Topic 7, *Spiritual Care Services*).
- 12.27 Providers should ensure families and carers have access to professionals capable of providing confidential emotional support and, if there is variance between the needs, choices and judgements of a family member or carer and those of the patient, the professional is independent of normal services offered to the patient.
- 12.28 Some family members and carers will require care and support from a health or social care professional capable of dealing with complex family situations. Providers should ensure they have access to individuals and teams with the requisite skills and knowledge to offer social support, spiritual support, specialist palliative care or psychological support services. Criteria and routes for referral should be agreed between different services.
- 12.29 Teams should ensure they have the ability to offer information and training on practical issues to carers who are looking after patients requiring extra help with activities of daily living or approaching the terminal stage of illness. This might include manual handling, managing distressing symptoms and dealing with incontinence and other body fluids. As death approaches, they should also be given information about what to expect and what to do after the death.

### **Bereavement support**

- 12.30 A three-component model of bereavement support should be developed and implemented in each Cancer Network to ensure that people's individual needs are addressed through variety in service provision. Cancer Networks should take account of the standards for bereavement care developed by the National Bereavement Consortium<sup>5</sup>. The components should be flexible and accessible when needed around the time of bereavement.

**Component 1** Grief is normal after bereavement and most people manage without professional intervention. Many people, however, lack understanding of grief after immediate bereavement. All bereaved people should be offered information about the experience of bereavement and how to access other forms of support. Family and friends will provide much of this support, with information being supplied by health and social care professionals providing day-to-day care to families.

**Component 2** Some people may require a more formal opportunity to review and reflect on their loss experience, but this does not necessarily have to involve professionals. Volunteer bereavement support workers/befrienders, self-help groups, faith groups and community groups will provide much of the support at this level. Those working in Component 2 must establish a process to ensure that when cases involving more complex needs emerge, referral is made to appropriate health and social care professionals with the ability to deliver Component 3 interventions.

**Component 3** A minority of people will require specialist interventions. This will involve mental health services, psychological support services, specialist counselling/psychotherapy services, specialist palliative care services and general bereavement services, and will include provision for meeting the specialist needs of bereaved children and young people (being developed as part of the National Service Framework on children and not covered here).

- 12.31 Provider organisations should be equipped to offer the first component of bereavement support and have strategies in place to access the other components. Services should be accessible from all settings.
- 12.32 Within the context of family and social support assessments, health and social care professionals involved in delivering care in the terminal phase of illness should assess individual and family coping ability, stress levels, available support and actual and potential needs with respect to the anticipated or actual bereavement.
- 12.33 Cancer Network-wide protocols should be developed to inform the level of bereavement support offered and the need for follow up and specialist referral, particularly for those at risk of complicated grief reactions. They should apply wherever the patient dies – at home, in hospital, hospice or care home – and should include a system to engage proactively with those assessed to be at risk, involving, for example, follow-up telephone calls or letters to individuals around eight weeks after death. Issues of consent and data protection should be considered carefully.

- 12.34 Providers should ensure that a leaflet is made available to families and carers around the time of the bereavement. Ideally, this should be developed locally, agreed by those involved in the provision of bereavement services, and include information on anticipated feelings and how to access local and national services.

### **C.3 Workforce development: specific recommendations**

- 12.35 Workforce Development Confederations in England (and the Workforce Development Steering Group in Wales), working with Cancer Networks, should ensure that all health care professionals involved in the delivery of supportive and palliative care services have access to basic training in understanding and meeting the needs of families and carers. This should include knowledge to underpin the delivery of ethnically and culturally sensitive care. They should also ensure ongoing education and training about bereavement and loss are available. The aim should be to enable professionals to develop a basic knowledge of characteristics increasing vulnerability to the loss experience or which impede adjustment to bereavement, and to help to recognise their own needs for further education and support.
- 12.36 Providers should ensure all staff working with people who are dying have access to a range of opportunities to address concerns and explore the difference between personal and professional responses to loss. This might involve a number of processes, such as clinical supervision and one-to-one and group support.
- 12.37 Specialist bereavement services should be sufficiently resourced to enable them to contribute to the preparation and ongoing support of health and social care professionals in relation to this aspect of care.
- 12.38 Those who offer bereavement services that include volunteer support workers should ensure mechanisms for recruiting, training, supervising and managing volunteers are in place. It is desirable that the workforce reflects the gender, age distribution and ethnicity of the clients they serve.

### **C.4 Research and development: specific recommendations**

- 12.39 Empirical research is needed to map the carer pathway, to identify views about different services and patterns of care received and how services can best meet their needs.

- 12.40 Evaluative research is needed to determine the cost-effectiveness of different models of providing support, tailored to different groups of families and carers.
- 12.41 Evaluative research is needed to compare different models of bereavement support for different groups, in particular one-to-one versus group sessions and volunteers versus professionally driven services.
- 12.42 Research is needed to determine in which situations and for which groups of people bereavement support is needed.

## D. Evidence

- 12.43 Some research has been undertaken on services to meet the needs of carers during the time they are looking after a patient, when the cared-for person is terminally ill and at the point of bereavement. There are a few randomised controlled trials (RCTs) and many of the studies involve small sample sizes and insensitive outcome measures, with a reliance on descriptions and formative evaluations. One systematic review has examined interventions for carers of patients using home cancer and palliative care services.

### D.1 Services for carers of patients with cancer

- 12.44 Home care services for patients generally include carer support in their aims. Carers report high satisfaction with such services and describe them as useful in helping them to look after patients, but they do not meet many of carers' own needs [B]. One RCT found that a home care nursing service raised the well-being of carers in the first three months after a patient was discharged, although this was lowered among those with physical problems of their own [A]. An education programme for carers of patients with cancer may have helped them to cope, with their perception of the burden of caring not worsening even when caring tasks increased in intensity.
- 12.45 Respite services can take many forms. Research suggests that carers of patients with cancer can be very ambivalent about leaving the patient, and such care may not be accessible to those who wish to remain in the home. Evaluations of two sitting services nevertheless found a high degree of satisfaction among carers, with the great majority feeling able to leave the patient with the sitter [B]. Research on massage, intended to provide a form of respite to carers, found it reduced emotional and physical stress, physical pain and sleep difficulty [B].



- 12.46 Social networks and activities can be an important source of support to carers. An 'activation programme' to increase the social activity of carers of patients with cancer was found to significantly increase their social activities during the treatment period [A].
- 12.47 One-to-one interventions are intended to provide a means of providing support and building problem-solving skills. The results of two RCTs of such services, however, are not promising: in one, the service appeared effective only for a distressed sub-sample; in the other (offering psychotherapy to spouses of patients with lung cancer), there was no visible impact. There was also low uptake of the latter service [A]. Research on a family education programme on the management of cancer-related pain, however, found significant improvements in knowledge, pain management and carer burden following its completion [B].
- 12.48 There has been more research on group interventions for carers of patients with cancer or who need palliative care. Although carers' groups may not be appropriate for all carers, the benefits of sharing information and practical and coping skills can be great. One RCT of a stress and activity management group for spouses found that those who attended had significantly higher knowledge scores, became more active, coped better with medical situations and were more satisfied with care provided than a control group, although psychosocial adjustment did not alter between the two groups [A]. Other studies on various kinds of group sessions for carers of patients with cancer have had mixed results. Some have shown no difference in quality of life or coping strategies; some have been found to provide support, facilitate coping and reinforce confidence; and others have been found to increase the anxiety of at least a sizeable minority of participants [B]. There can be considerable difficulties in recruiting carers to take part.

## **D.2 Care at the point of terminal illness**

- 12.49 Several studies have considered provision for carers at the time of terminal illness, together with its effectiveness. Carers' needs are viewed as part of terminal care, but many services did not assess carers' needs.
- 12.50 Three RCTs have assessed the impact of interventions to assist both carers and patients. They clearly suggest that good care prior to a patient's death, whether in hospital or at home, can reduce the carer's anger and distress during bereavement. Another study had similar results, although it focused on physiological changes among those involved [A].



- 12.51 Several studies have examined carers' responses to particular forms of terminal care. One found no difference in anxiety levels or social participation among carers of patients in a hospice compared to those of patients using conventional care [B]. An evaluation of a home hospice service found that carers' quality of life remained stable over a period of four weeks [B]. An RCT of a hospital-at-home service for terminally ill patients found carers had greater satisfaction with the care provided, although there was no increased likelihood of patients remaining at home in the last two weeks [A].

### **D.3 Support in bereavement**

- 12.52 The evidence on terminal care supports the view that it should be seen as part of bereavement care, as carers' levels of emotional distress are affected by the care provided before death. A few studies have examined the impact of particular strategies to offer support in bereavement, with mixed results. Research on bereavement counselling found no impact for those involved [B], whereas a study of telephone contact between ward nurses and grieving families found this reduced sense of despair and detachment [B]. Involvement in a support group has been shown to have a statistically significant impact in terms of satisfaction and diminished needs for other support, although such positive effects may take time to appear [B].
- 12.53 Studies underscore the need to assess carers' needs with respect to bereavement along with the potential for experiencing difficulties adjusting to their loss. Individual clinical judgement is currently the most effective way of identifying those at risk, as risk assessment tools cannot be relied upon as a predictor of outcome [B]. This emphasises the need to ensure training and support for those involved in this process.
- 12.54 An RCT of a programme to prevent mental health problems in children who had experienced the death of a parent had encouraging results, in that the programme was able to modify the warmth of the parent-child relationship and decrease symptoms in the children [A].

### **D.4 General issues**

- 12.55 A range of models for providing help to carers has been identified, but no single service model will be acceptable to all carers, or meet all needs of individual carers. The evidence of unmet need among carers using home palliative care services highlights the limited scope of this type of intervention for them. An expansion of such services to include multidisciplinary support for carers, independent of patient care, might help to meet carers' needs.

- 12.56 The evidence for one-to-one therapeutic interventions for carers is currently unclear. From the two published trials, only one found benefits for the intervention group, and this was for a significantly depressed sub-sample. Group interventions may be more successful, with the only controlled trial suggesting that carers gain both information and social activities. These tend to have fairly low uptake, however. The challenge of providing support may be greatest in rural areas, and it is important that carers are informed of the possibility of informal peer support, local and national telephone helplines and existing social networks.
- 12.57 Research suggests that practitioners planning to develop interventions for carers must ensure the interventions focus specifically on the needs of carers (that is, they do not provide a generic service), address issues of access and acceptability, have clear and modest aims and are evaluated using rigorous evaluation methods.

## E. Resource implications

- 12.58 Additional posts will be required to undertake the role of strategic development of services for families and carers. The estimated cost is £3.4m.
- 12.59 The Guidance recommends a three-component model of bereavement support. The cost of provision of bereavement services for Component 2 only (those bereaved people who require additional support to help them deal with the emotional and psychological impact of loss by death) is estimated to be around £16.1m. Component 1 (information about grief and how to access support services) and Component 3 (specialist interventions for a small proportion of bereaved people) services are incorporated in the resource implications sections of Topic 4, *Information* and Topic 5, *Psychological Support Services* respectively.
- 12.60 The provision of high quality bereavement support interventions for selected 'at risk' people may significantly reduce use of health services, particularly GP visits. These cost savings are not known with certainty and have not been taken into account.
- 12.61 Basic training in understanding and meeting the needs of carers and families is required for all health care professionals involved in the delivery of supportive and palliative care.

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# 13. Research in Supportive and Palliative Care: current evidence and recommendations for direction and design of future research

## A. Introduction

- 13.1 Research in supportive and palliative care in cancer is somewhat different to research in other areas of cancer care. This topic examines current conclusions about the evidence underpinning service configurations for supportive and palliative care, arising from the systematic review undertaken to develop the Guidance recommendations. General recommendations are offered on the direction and design of research in this field; specific recommendations for research are included within each topic area.

## B. The quality of current research evidence

### **B.1 Nature of the evidence**

- 13.2 Research evidence in supportive and palliative care addresses three main themes: the need for such care, its importance to those affected by cancer (and to society), and effective solutions.
- 13.3 There is ample evidence of need for good supportive and palliative care among patients with cancer. This is shown in studies over many years demonstrating problems in communication, information, psychological, social and spiritual support, symptom control, palliative care, care of patients who are dying, bereavement support and care for patients and families. It has also shown the need to involve users in service planning and to orientate services around the issues faced by patients and families.

- 13.4 Studies have indicated that palliative and terminal care, including good communication, are among the top fifteen health care priorities identified by members of the general public.
- 13.5 The research evidence on effective solutions to meet these many needs is weaker. This may be due in part to low investment in research in this area, particularly in some fields. Nevertheless, there is extremely good evidence of effectiveness in some areas, particularly if both randomised and observational studies are included. In areas such as information giving, communication, specialist palliative care and psychological support, experimental randomised controlled trials and observational studies indicate that training, professional interventions and particular services can help to alleviate difficulties experienced by patients and families.
- 13.6 The evidence is less clear on the details of interventions and on the particular groups of individuals likely to benefit. Recommendations on future support and research are discussed below.

## **B.2 Interventions**

- 13.7 There are two main difficulties relating to evidence on interventions in supportive and palliative care. First, in many instances, an intervention is not clearly described. This is a common problem, arising from a lack of publishing space within journals and a view that detailed accounts of an intervention are not likely to be of great interest to an international readership. This makes drawing conclusions about the relevance of an intervention in different circumstances and settings very difficult. It also limits the ability of other researchers to reproduce an intervention independently and accurately in another setting.
- 13.8 Second, interventions are often highly variable from one setting to another, limiting the ability to draw general conclusions about their overall effectiveness. This problem is clearly demonstrated in the area of specialist palliative care, where teams work in different ways, with different policies, different staff mixes and different training backgrounds, making it difficult to determine the best model of working.
- 13.9 There are few studies that compare different aspects of an intervention, such as addressing the best way to provide training or care. In some areas, however, an early trial has mapped the exact nature of an intervention, allowing subsequent studies to test it in a wider context. A good example is research on communication skills training.

### **B.3 Populations**

- 13.10 Conducting research on patients who are highly distressed, have severe symptoms or who are dying is very difficult. Many studies were found to make rigorous attempts to recruit from representative samples of patients and families and to collect data in an ethical, sensitive and meaningful way.
- 13.11 It was clear from some of the research that interventions found to be effective earlier in care needed to be replaced or modified in advanced disease or with particular groups such as older people or those from diverse cultural or ethnic backgrounds. There was very limited research into the preferences of individuals from different cultures and in the oldest age groups with respect to interventions.

### **B.4 Study design**

- 13.12 Although the systematic review did not specifically search for qualitative work, the strategy elicited both quantitative and qualitative research. Some studies used the technique of triangulation, combining data from both quantitative and qualitative sources.
- 13.13 NICE guidance provides an hierarchy of research according to study design, with a well-designed experimental study – and, in particular, a randomised controlled trial – providing the highest-level evidence. In contrast, lowest-level evidence is drawn from consensus among professionals and/or service users. While this hierarchy is useful, it takes no account of the relevance of individual studies to the problem affecting patients and families, nor of the health care context in which the service is operated.
- 13.14 A further issue is the integration of qualitative studies with other findings. Qualitative designs can examine the effectiveness of interventions and provide more detailed interpretations of need or more detailed descriptions of interventions. Currently, no robust hierarchy of qualitative studies examining the effectiveness of interventions is available. It is possible to use qualitative research to compare interventions.

### **B.5 Outcome measurement**

- 13.15 Devising outcome measures that are sensitive and appropriate to the intangible nature of critical issues, such as symptom control, psychological well-being, quality of life, quality of death and quality of care, is a major challenge in the field of supportive and palliative care.

- 13.16 Great progress has been made in developing robust and sensitive outcome measurement, but in many areas these are still relatively crude. In addition, many important services do not routinely collect information about their outcomes in the way that biological markers and clinical parameters are recorded in other clinical settings.

## **B.6 Systematic review methods**

- 13.17 Some specific difficulties were encountered by the systematic review. First, the electronic database searches and search strategy did not detect all important studies, including some important randomised controlled trials. It is likely that some of the key words and search terms used in this area do not always detect the important studies. The search therefore had to be augmented by consultation with experts, 'grey' literature searches and follow-up of references. The database of evidence should be a resource for others in the future, but it will require updating, as new studies were emerging during the course of the project.
- 13.18 Given the number of qualitative studies in this field, it would be timely to conduct some qualitative reviews, particularly in those areas where quantitative data are limited. These could include, for example, spiritual support, social support and user involvement. Such work would require not only a new review, but also development of qualitative systematic review methodologies, such as the conduct of a meta-ethnography.

## **C. Recommendations**

### **C.1 Direction of research**

- 13.19 Future research should focus on determining effective solutions, rather than re-assessing need; there is a wealth of evidence on need and importance, and a relative dearth on effective solutions.
- 13.20 Evaluative research to determine which interventions are most effective (and cost-effective for different patient groups at different stages of disease) should also be pursued.
- 13.21 Research funders should invest in longitudinal studies of patient and carer experiences and expectations of illness and health and social care, to describe changes in perspectives as illness evolves and the best ways of meeting needs at different points in time.
- 13.22 New services and many existing services should be developed (or continue to be developed) within a rigorous and properly funded evaluation framework.

- 13.23 Research funders should invest in research programmes in supportive and palliative care. These should be sufficiently substantial, sustained and robust to ensure that studies measure aspects of services important to users, determine effectiveness and collect information on patient experience, and achieve appropriate power.

## **C.2 Interventions**

- 13.24 Detailed descriptions of interventions and service configurations should be made available when evaluations are published.
- 13.25 Wherever possible, studies should use a research base to develop interventions, building on existing research and indicating where interventions deviate from those already established.
- 13.26 Future research should compare different service configurations and interventions.

## **C.3 Populations**

- 13.27 Clear descriptions need to be offered of populations seen by individual services and how these compare with the general population.
- 13.28 Future research should investigate effective care for those from diverse cultures.

## **C.4 Outcome measures**

- 13.29 A system of routine collection of some limited outcome information should be included in the care of patients with cancer, in addition to biological markers.
- 13.30 Prospective measures of outcome which reflect patients' and carers' experiences at all stages of disease should be further refined and developed.
- 13.31 Work to develop a core set of person-centred outcome measures robust enough to capture changes over time, for worse or better, should be pursued.

## **C.5 Systematic review methods**

- 13.32 Future reviews should explore ways to combine scores of a traditional hierarchy of evidence, based on study design, with an estimate of the pertinence or relevance of the study using, for example, some kind of signal score.
- 13.33 Systematic review methods and hierarchies that can include high quality qualitative research need to be developed and tested.



# Summary of Recommendations

## A. The Department of Health and the Welsh Assembly Government

### **The Department of Health and the Welsh Assembly Government should:**

Oversee the implementation of this Guidance by:

- developing standards related to supportive and palliative care for patients with cancer which take account of recommendations in this Guidance
- ensuring quality assurance programmes are in place to monitor progress towards achievement of recommendations
- ensuring mechanisms are in place to monitor changes over time in patients' experience of care
- ensuring necessary workforce and accredited training programmes are in place to achieve recommendations.

### **In addition, they should ensure that:**

Work is commissioned to scope assessment approaches/tools suitable for use in routine practice by a range of health and social care professionals (1.16).

Research is commissioned in areas pertinent to supportive and palliative care (see Topic 13).

A comprehensive range of high quality information products is available for people with cancer (4.15), including a national core set of accredited information materials, available in translation, for people from black and ethnic minority communities (4.16).

A process is in place to accredit organisations producing information related to cancer (4.15).

## B. Commissioners

### **Commissioners, working through Cancer Networks, should ensure that:**

#### *Co-ordination of care*

Structures and processes are in place to plan and review local supportive and palliative care services (1.12).

All relevant stakeholders are involved in the planning and review of services. These include (1.12):

- patients and carers (through Partnership Groups)
- voluntary sector providers
- NHS organisations and teams
- Workforce Development Confederations/the Workforce Development Steering Group
- councils with social service responsibilities
- representatives of Cancer Services Collaborative 'Improvement Partnerships'.

Cancer Network-wide audits of patients' experience of care are undertaken (1.37).

Strategies that identify service planning needs of people within local communities who are socially excluded and who have difficulty accessing services are developed (1.12).

#### *Information*

An adequate range of information materials is available to patients, free at the point of delivery (4.17).

#### *Psychological support*

All patients have access to an appropriate level of psychological support, as described in the four-level model of professional psychological assessment and intervention set out in this Guidance (5.17).

Emergency psychological support services are available and that health care professionals have 24-hour, seven days a week access to advice on caring for patients who have acute psychological and/or psychiatric problems (5.35).

### *Social support*

Collaborative working relationships with local authorities are established to facilitate the delivery of social care to patients and carers (6.15).

Different components of social support are available within a Cancer Network and are accessible from all settings, domestic or institutional (in conjunction with social care services) (6.16).

### *Spiritual support*

Multidisciplinary teams have access to suitably qualified, authorised and appointed spiritual care givers (7.19).

### *General palliative care, including care of dying patients*

Policies for the provision of out-of-hours palliative care to patients with cancer are developed, underpinned by assessment of local needs and deficiencies (8.23).

Medical and nursing services are available on a 24-hours, seven days a week basis for patients with advanced cancer living at home (8.24).

Provision is made for continuous support in patients' homes for those who are approaching the end of life and wish to die at home (8.36).

Equipment needed to enable patients to live in the community is available within an agreed timescale (8.28).

### *Specialist palliative care*

Teams are sufficiently staffed to undertake face-to-face assessments of people with cancer (at home or in hospital) during the hours of 09.00-17.00, seven days a week (9.32).

Specialist palliative care beds (in hospices or hospitals) are available in each Cancer Network and are sufficient in number to meet the needs of the population served (9.35).

### *Rehabilitation*

All patients who need them have access to rehabilitation services (10.19).

### *Complementary therapies*

Decisions are made on what, if any, complementary therapies should be funded for particular groups of patients (11.12).

### *Services for families and carers, including bereavement care*

Information, support (including practical help and respite arrangements) and bereavement services are in place for families and carers (12.18).

## C. Cancer Networks

### **Cancer Networks, as partnerships of organisations and service users, should ensure that:**

#### *Co-ordination of care*

A unified approach to the assessment of patients' needs is adopted across the Cancer Network. This will require agreement on which tools should be used in specific circumstances (1.17).

Up-to-date service directories are available. These should include information on local self-help and peer-to-peer support groups, user groups and advocacy groups, information services, psychological support services, social support services, spiritual care, specialist palliative care services, rehabilitation, complementary therapies, services for families and carers and local and national telephone helplines (1.24/2.20).

#### *User involvement*

Partnership Groups that involve patients, carers and practitioners are established and supported, and their views are taken into account when services are planned (2.16).

Members of Partnership Groups (users and professionals) have access to training and support (2.27).

#### *Information*

A lead for cancer information is nominated (4.29).

Local policies regarding cancer information materials are developed (4.18).

#### *Psychological support*

Referral criteria for specialist psychological support services are developed (5.23).

#### *Social support*

Joint reviews of community equipment services for people with cancer are performed (6.17).

#### *General palliative care, including care of dying patients*

Protocols/guidelines on symptom control, palliative interventions and care of dying patients are developed (8.20/8.21).

#### *Specialist palliative care*

All specialist palliative care providers within the Cancer Network develop common approaches to the assessment, treatment and care of patients. This should lead to the publication and dissemination of guidelines, protocols and care pathways as appropriate (9.25).

Guidelines that set out admission (9.38) and referral (9.24) criteria for specialist palliative care are developed.

### *Rehabilitation*

A lead advanced practitioner allied health professional is identified to work with the Cancer Network management team on devising a Cancer Network-wide strategy for rehabilitation and a network-wide assessment tool (10.20).

Assessments of patients' rehabilitation needs are based on the four-level model of rehabilitation assessment and support described in this Guidance (10.22).

### *Complementary therapies*

Policies designed to ensure best practice for practitioners practising complementary therapies within NHS organisations are developed (11.11).

### *Support for families and carers, including bereavement care*

A three-component model of bereavement support, based on the model described in this Guidance, is developed and implemented (12.30).

Cancer Network-wide protocols on bereavement support, follow-up and specialist referral are developed (12.33).

## D. Provider organisations

### **Individual provider organisations should ensure that:**

#### *Co-ordination of care*

One or more individuals is/are nominated to lead on supportive and palliative care services (1.15).

#### *User involvement*

An individual is nominated to take the lead on developing and sustaining user involvement (2.21).

Mechanisms are developed to ensure the views of patients and their carers are elicited and taken into account (2.22).

Work is progressed with local self-help and support groups to establish the most effective ways of supporting their activities (2.24).

#### *Face-to-face communication*

Interpretation services are available during key consultations (3.21).

Services are available for people with hearing, sight, speech or combined sensory difficulties and for people with learning disabilities (3.24).

Members of staff who may benefit from communication training are identified (3.28).

Systems to evaluate how effectively staff communicate (such as performance appraisal) are established (3.28).

#### *Information*

A nominated lead for cancer information is appointed (with Cancer Networks) (4.29).

Mechanisms to ensure that patients and carers have access to a range of high quality information materials about cancer and its treatment are developed in a variety of formats (4.20).

Arrangements are in place to translate information materials (4.24).

#### *Psychological support*

Appropriate facilities, fit for purpose, are available for undertaking psychological assessments and interventions (5.37).

#### *Social support*

Patients, carers and health care professionals have ready access to social workers (6.21).

Health care staff know how to secure specialist social care assessments (6.28).

Access for patients and carers to information about social care (6.24) and to the different types of social support available to them (6.25) is facilitated.

#### *Spiritual support*

They adhere to the framework of best practice in meeting the religious and spiritual needs of patients and staff outlined in NHS national guidance (7.20).

A staff member is nominated to take responsibility for liaising with local faith leaders (7.20).

Patients and carers are offered information on how to access spiritual help and support (7.15).

An appropriate space is available for use by various faith groups (7.22/23).

#### *General palliative care, including care of dying patients*

All multidisciplinary teams implement managed systems of caring for dying patients (8.33).

### *Rehabilitation*

Suitable facilities are available and equipment is readily accessible to support effective and safe rehabilitation (10.30).

Robust systems of forward planning which account for patient needs for appliances such as wigs, stoma bags, lymphoedema hosiery and prostheses are in place (10.31).

### *Complementary therapies*

Patients have access to high-quality information about complementary therapy services (11.13).

Any practitioner delivering complementary therapies conforms to policies agreed by the Cancer Network (11.15).

### *Services for families and carers, including bereavement care*

A lead is nominated to oversee the development and implementation of services for families and carers (12.19).

Families and carers are offered a separate assessment when they provide substantial amounts of care, in accordance with the Carers (Recognition and Services) Act 1995 (12.21).

Provision is made for families and carers to meet with others who have had similar experiences, if wished (12.25).

Families and carers have access to personnel who can offer support for complex needs (12.28).

A leaflet providing key information is available for families and carers around the time of bereavement (12.34).

Staff working with people who are dying have access to appropriate support (12.36).

### **Primary Care Organisations/Local Health Boards should ensure that:**

Access to medications that may be required in patients' homes is available on a 24-hour, seven days a week basis (8.37).

### **Acute NHS Trusts should ensure that:**

Flexible systems are in place to obtain rapid discharge of patients who wish to die at home (8.35).

### **In-patient specialist palliative care service providers should ensure that:**

They can provide care for patients with complex problems (9.20).

They have levels of core staff sufficient to provide a specified level of service and access to a range of other specialist expertise (9.27/9.29).

## E. Multidisciplinary teams/services

**Each multidisciplinary team (such as breast, colorectal and lung cancer teams and primary care teams) and each specialist service (radiotherapy, chemotherapy and palliative care, for instance) should ensure that:**

### *Co-ordination of care*

Referral guidelines for the services they offer are developed (1.23).

Patients and carers are provided with information on whom to contact locally if they have particular questions about their treatment and care (1.25).

Structured assessments of patients' needs are undertaken and recorded at key points in the patient pathway (1.19). These assessments should encompass needs related to information, communication, psychological support, social support, spiritual support, palliative care and rehabilitation (1.18).

Individuals' needs for support are discussed at multidisciplinary team meetings and the outcomes of these discussions are recorded (1.26).

Policies/protocols in relation to communication and other key aspects of supportive and palliative care are developed (1.27).

They are able to identify patients under their care (1.28).

Mechanisms to develop continuity of care are promoted, including the possibility of nominating an individual to take on a 'key worker' role with respect to individual patients (1.29).

An individual is identified to act in the capacity of administrative contact for patients and professionals (1.30).

Other teams/services with which they most frequently interact are identified and joint plans to promote co-ordinated care are developed (1.33).

Mechanisms are developed to ensure timely transfer of information about patients (electronic transfer and patient held records, for instance) (1.34).

### *User involvement*

Mechanisms are developed to gather the views of patients and carers on a regular basis (2.23).

Mechanisms are developed to enhance patient access to peer-to-peer support, recognising the cultural sensitivities of patients (2.26).



### *Face-to-face communication*

Face-to-face communication at key points in the patient pathway involves (wherever possible) a senior clinician. This clinician should have expertise in the relevant disease and in options for treatment and care and should have received advanced communication skills training (3.18).

Patients are enabled to review what they have been told during key consultations at a later date should they so wish (3.20).

### *Information*

Information needs and preferences of patients and carers are assessed on an ongoing basis (4.21).

An individual is nominated to take a lead on information and to implement policy at local level (4.30).

Patients and carers have the opportunity to talk through the information they have been given with health or social care professionals. Patients should also have their attention drawn to other sources of assistance to help them understand and interpret information, such as voluntary sector helplines or information services (4.22)

They are familiar with local patient information resources and are able to provide relevant materials to patients (4.28).

### *Psychological support*

Patients are systematically screened for psychological problems at key points in the patient pathway (5.26).

Patients are made aware of the wide range of support services available after cancer treatment has ended (5.39).

An individual (or individuals) who can provide Level 2 psychological care is (are) identified (5.42).

Mechanisms are established to promote joint working among teams caring for people with cancer who develop mental health problems and those working with people with mental health problems who develop cancer (5.36).

### *Social support*

Patients' social needs are identified as part of initial routine assessment and then assessed on an ongoing basis (6.18).

Mechanisms are established to promote effective working relationships with social services departments (6.22).

### *Spiritual support*

Patients and carers are offered information about spiritual support services (7.15).

*General palliative care, including care of dying patients*

Mechanisms are developed for the transfer of relevant clinical information between teams providing care during normal working hours and out-of-hours services (8.26).

Means are developed to identify patients with advanced cancer who have care needs (8.27).

*Rehabilitation*

Arrangements are made for patients to have their rehabilitation needs assessed and met (10.22)

Patients are given opportunities to prepare for their life after treatment, including support and advice on employment, financial difficulties and personal relationships (10.27)

Allied health professionals are part of site-specific multidisciplinary team meetings as appropriate (10.29).

*Services for families and carers, including bereavement care*

Families and carers have regular opportunities to discuss their concerns with team members (12.20) and are offered information on a variety of topics (12.22).

They can offer families and carers information and training on practical care issues (12.29).

## F. Individual health and social care professionals

### **In order to help achieve quality care for patients and carers, individual health and social care professionals must:**

Have necessary skills to conduct assessments and meet needs in partnership with patients and carers (1.18/1.22).

Document accurately patients' identified needs (1.19).

Make necessary referrals to other services (1.23).

Communicate with other members of the multidisciplinary team (1.26).

Ensure they have the necessary education and training and ongoing support and supervision to meet the needs of patients and carers under their care.

## G. Workforce Development Confederations/ the Workforce Development Steering Group

### **Workforce Development Confederations/the Workforce Development Steering Group (working with Cancer Networks) should:**

Assess the need for, and plan the development of, each of the professional groups who contribute to supportive and palliative care.

Make provision for skills training in the assessment of needs of patients, families and carers generally, and specifically, in relation to:

- information needs and preferences
- psychological care
- social care
- spiritual care
- rehabilitation
- cultural diversity.

### **In addition, they should ensure that:**

#### *Face-to-face communication*

Accredited training courses on communication skills are made available for staff (3.25) and, in collaboration with Cancer Networks, staff groups are prioritised for communication training (3.27).

#### *General palliative care services, including care of dying patients*

All relevant staff are trained in best practice regarding the care of dying patients (8.40).

Priorities for training staff in palliative care are identified (8.38).

#### *Rehabilitation*

Education and training provision is adequate to meet the demands of the four-level model of rehabilitative assessment and support (10.35).

## Appendix 1

# How the Guidance was Produced

### A1

#### **User involvement**

- A1 The involvement of people with cancer and their carers has been central to the process of producing the Guidance. Among their contributions has been:
- involvement in the initial proposal-generating event and a parallel survey of service users carried out by Cancerlink to guide and inform the Guidance development process
  - active participation on the Editorial Board (Appendix 2.1)
  - representation on a User Reference Group (Appendix 2.2) who met twice during the process and commented and contributed to successive drafts of the Guidance
  - significant involvement at different consultation stages prior to publication of the Guidance.

#### **Stages in the process**

- A2 The first stage was a two-day residential event at which a large group of relevant health and social care professionals, people with personal experience of cancer, health care commissioners and academics from around the country met to put forward structured proposals based on their experience and knowledge. The proposals were set out in a common format, which included key elements such as the evidence on which they were based, implications for the NHS, and relationships to outcomes.
- A3 The proposals were sent to referees representing a spectrum of clinical opinion, those likely to use the Guidance, and organisations and individuals representing concerns of patients and carers. The original proposals and referees' comments then went forward to the evidence review stage.

- A4 The Editorial Board, who oversaw the development of the Guidance, reflected on the proposals and relevant comments from referees with the Guidance Development Team (Appendix 2.3) and drafted preliminary recommendations designed to inform and direct the task of reviewing the literature. This evidence was assessed by the Editorial Board and was used to further refine the recommendations. At a relatively early stage in Guidance development, the recommendations were also scrutinised by two sets of reference groups, one of representatives of commissioners and providers (Appendix 2.4) and the other of service users (Appendix 2.2). An Allied Health Professionals (AHP) reference group (Appendix 2.5) was also established to review the Guidance during development.
- A5 The guidance was subject to the NICE consultation process (see NICE website for details – [www.nice.org.uk](http://www.nice.org.uk)). In addition, individuals were invited to comment by the Guidance Development Team (see Appendix 2.1).

### **The evidence review**

- A6 Systematic reviews of the research literature were then carried out by the Evidence Review Team (Appendix 2.6) based at the Department of Palliative Care and Policy, King's College, London.
- A7 The task of the Evidence Review Team was to prepare a systematic assessment of the nature and strength of the evidence underlying the recommendations developed by the Editorial Board and Guidance Development Team, based on the original proposals. This work is summarised in *The Research Evidence*.
- A8 The quality of individual research studies was graded following the criteria listed in Table A.1. This is the same system used in the reviews undertaken by the NHS Centre for Reviews and Dissemination at the University of York as part of the site-specific *Improving Outcomes* series<sup>1</sup>.

A1

<b>Table A.1 Evidence grades</b>	
<b>Grade I (strong evidence) – randomised controlled trial or review of randomised controlled trials</b>	
Ia	Calculation of sample size and standard definition of outcome variables
Ib	Accurate and standard definition of outcome variables
Ic	Neither of the above
<b>Grade II (fairly strong evidence) – prospective study with a comparison group (non-randomised controlled study or good observation study)</b>	
IIa	Calculation of sample size and accurate, standard definition of outcome variables and adjustment of the effects of important confounding variables
IIb	One of the above
<b>Grade III (weak evidence)</b>	
IIIa	Comparison group, calculation of sample size and accurate, standard definition of outcome variables
IIIb	Two or more of the above
IIIc	None of these
<b>Grade IV (weak evidence) – Cross-sectional study</b>	

A9 The quality of combined research was also graded using the hierarchy of evidence employed in the *Improving Outcomes* manuals<sup>1</sup>:

- A – evidence derived from randomised controlled trials (RCTs) or systematic reviews of randomised trials
- B – evidence from non-randomised controlled trials or observational studies
- C – professional consensus.

A10 These are broad categories and the quality of evidence within each category varies widely. It should not be assumed that RCT evidence (Grade A) is always more robust than evidence from observational studies (Grade B).

A11 The quality of research evidence forms a continuum. It is categorised here for convenience, but there is overlap between categories. Much of the published research on supportive and palliative cares focuses on clinical evaluations of treatment and care; little direct research has been carried out on the organisation and delivery of services. Moreover, as previously recognised in the site-specific guidance series for many service delivery issues, randomised controlled trials (categorised here as the highest quality evidence) may not be feasible. Research designs that might be regarded as being of relatively poor quality for evaluating a clinical intervention may therefore be the most reliable available for assessing the effectiveness of service delivery.

A12 Complementary research, designed to quantify the potential cost of implementing key aspects of the guidance, was carried out by the School of Health and Related Research (ScHARR) at the University of Sheffield (see Appendix 2.3).

## Outcomes of the process

A13 The process culminated in the production of three large sources of information: *The Guidance Manual*, which is based on all the available sources of information; *The Research Evidence*, a condensed version of systematic reviews of research used to inform the guidance and published in electronic format (see: [www.nice.org.uk](http://www.nice.org.uk)); and *The Economic Review*, also published in electronic format. There is also a Public Version of the Guidance intended for patients and the wider public, which sets out a short summary of the key recommendations, and a stand-alone version of the Executive Summary.

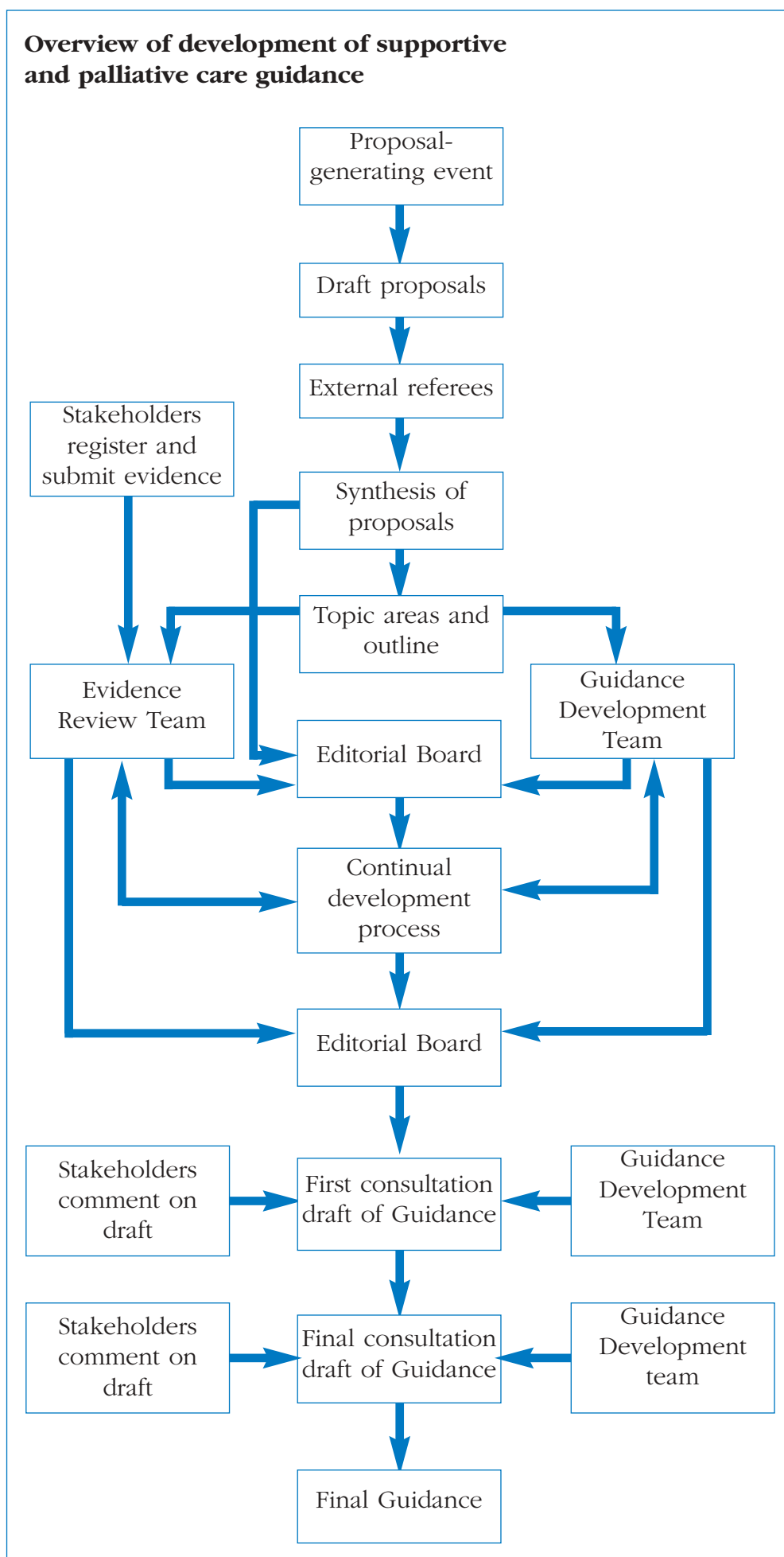
A14 The production of the Guidance was funded by the National Institute for Clinical Excellence (NICE).

A15 Figure A.1 depicts key stages in the development of the Guidance.

## Reference

1. Mann T. *Clinical Guidelines: using clinical guidelines to improve patient care within the NHS*. London: DoH. 1996.

**Figure A.1**





## Appendix 2

# People and Organisations Involved in Production of the Guidance

A2

- 1. Editorial Board**
- 2. User Reference Group**
- 3. Guidance Development Team**
- 4. Commissioner and Provider Reference Group**
- 5. Allied Health Professionals Reference Group**
- 6. Evidence Review Team**

## Appendix 2.1

# Membership of Editorial Board

A2

Ms Sylvia Berry	User representative
Ms Maggie Bisset	Nurse Consultant in Palliative Care, Camden and Islington Primary Care NHS Trust
Ms Jane Bradburn	Cancer Voices Consultant, Macmillan Cancer Relief
Dr Ged Corcoran	Macmillan Consultant in Palliative Medicine, University Hospital, Aintree
Prof. Lesley Fallowfield	Cancer Research UK Psychosocial Group, University of Sussex
Ms Kim Fell	Nottingham Cancer Centre Manager, Nottingham City Hospital and Queen's Medical Centre, Nottingham
Dr Rob George	Consultant in Palliative Medicine, Camden and Islington Primary Care NHS Trust
Ms Maureen Hunter	Assistant Director, Rehabilitation, The Royal Marsden Hospital NHS Trust, London
Dr Stephen Kirkham	Consultant in Palliative Medicine, Poole Hospital NHS Trust, Dorset
Prof. Sheila Payne	Professor in Palliative Nursing Care, Trent Palliative Care Centre, University of Sheffield
Prof. Amanda Ramirez	Professor of Liaison Psychiatry, Guy's, King's and St Thomas' School of Medicine, London
Prof. Mike Richards	National Cancer Director, Department of Health
Ms Frances Sheldon	Macmillan Senior Lecturer in Psychosocial Palliative Care, Department of Social Work Studies, University of Southampton
Mr Stewart Sinclair	Carer representative
Rev. Peter Speck	Former chaplaincy team leader, Southampton University Hospital NHS Trust and Hon.Senior Research Fellow, King's College, London
Dr Keri Thomas	Macmillan GP Advisor, National Clinical Lead for Palliative Care, Cancer Services Collaborative
Dr Rob Thomas	Consultant Oncologist, Addenbrooke's NHS Trust, Cambridge

In addition, the following people provided expert advice in relation to specific topic areas during the Guidance development process:

Ms Mary Casey	Cross Commission Palliative Care Lead, National Care Standards Commission
Dr John Ellershaw	Medical Director, Marie Curie Centre Liverpool, and Consultant in Palliative Medicine/Honorary Senior Lecturer, Royal Liverpool University Hospital NHS Trust
Mr Mike Fitzsimmons	Lead Therapist, Carer Services, Department of Palliative Medicine, Guys and St Thomas' NHS Trust, London
Ms Caroline Hoffman	Nurse Consultant (Rehabilitation), The Royal Marsden Hospital NHS Trust, London
Dr Sosie Kassab	Director of Complementary Therapy Services, Royal London Homeopathic Hospital NHS Trust
Ms Patricia Kearney	Director of Practice Development, Social Care Institute for Excellence (SCIE)
Dr Michelle Kohn	Complementary Therapies Medical Adviser, Macmillan Cancer Relief
Dr Barry Muir	Project Manager/Project Lead, Pathology Modernisation and National Cancer Workforce, North East London Workforce Development Confederation
Dr Marilyn Relf	Head of Education, Michael Sobell House, Churchill Hospital, Oxford
Mr Peter Tebbit	National Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care

## Appendix 2.2

# Membership of User Reference Group

A2

Louise Bass, Weston super Mare, Somerset  
Tom Bass, Weston super Mare, Somerset  
Sylvia Berry, Liverpool  
Andy Caswell, Rushden, Northants  
Anna Craven, Skipton, North Yorkshire  
Sara Crisell, Harwich, Essex\*  
Jeremy Gambrill, Cuckfield, West Sussex\*  
Devi de Silva, London  
Denise Fuller, Horsham, West Sussex  
Heather Goodare, Horsham, West Sussex  
Steve Hawley, Bromley, Kent  
Denise Hodkin, Rotherham, South Yorkshire  
Margaret King, UK Breast Cancer Coalition  
Hannah Lynes, Special Projects Officer, Help the Hospices  
Pete Madeley, Cottingham, East Yorkshire  
Judith McNeill, Head of Community Links, Macmillan Cancer Relief  
Delyth Morgan, Breakthrough Breast Cancer  
Joyce Pritchard, RAGE, Bromley, Kent  
Lindi Shaw, Rotherham, South Yorkshire  
Stewart Sinclair, London  
Barry Stables, Scarborough, Yorkshire  
Jayne Thomas, User Involvement Co-ordinator, National Council for Hospice and Specialist Palliative Care Services

The User Reference Group was facilitated by Ms Jane Bradburn, Cancer Voices Consultant, Macmillan Cancer Relief, and attended by Mrs Jo Luthert, Healthcare Consultant, London, and Damyanti Patel, Ethnic Minority Network Development Officer, Macmillan Cancer Relief.

\*Sadly, Ms Crisell and Mr Gambrill died before the Guidance could be published.

## Appendix 2.3

# Guidance Development Team

Prof. Alison Richardson	Professor of Cancer and Palliative Nursing Care, The Florence Nightingale School of Nursing and Midwifery, King's College, London (Lead)
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Ms Jane Bradburn	Cancer Voices Consultant, Macmillan Cancer Relief
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Mrs Jo Luthert	Healthcare Consultant, London
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Mr Alex Mathieson	Freelance Writer and Editor, Edinburgh
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Dr Ann Richardson	Independent Research Consultant, London
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**The economic analysis was commissioned from the School of Health and Related Research (SchARR), University of Sheffield:**

Ms Sue Ward	Senior Operational Research Analyst, Operational Research Department
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Mr Stephen Salzano	Senior Operational Research Analyst, Operational Research Department
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Ms Fiona Sampson	Research Fellow, Medical Care Research Unit
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Ms Johanna Cowan	Operational Research Assistant, Operational Research Department
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A2

## Appendix 2.4

# Membership of Commissioner and Provider Reference Group

A2

Dr Sheila Adam	Director of Public Health, North London SHA
Ms Elizabeth Andelin	Assistant Director of Patient Services, Bradford City PCT
Prof. Mark Baker	Director/Lead Cancer Clinician, Yorkshire Cancer Network
Dr Simon Balmer	Director of Public Health, Leeds North East PCT
Ms Judith Brodie	Head of Cancer Support Services, CancerBACUP
Mr Chris Bull	Chief Executive, Southwark PCT
Ms Penny Buchan	Director of Nursing and Health Improvement, Colchester PCT
Mr Derek Campbell	Chief Executive, Central Liverpool PCT
Ms Liz Cheesman	Senior Cancer Information Nurse, CancerBACUP
Dr Jane Chidgey	Lead Cancer Nurse, North East London Cancer Network
Ms Lisa Christensen	Executive Director, Social Services and Health Improvement, Lambeth Social Services
Dr Susan Closs	Consultant in Palliative Medicine/Clinical Director for Cancer Services, Swansea
Ms Maggie Crowe	Nurse Consultant, Royal United Hospital, Bath
Ms Moira Davison	Director, Northern Cancer Network
Dr Peter Elton	Director of Public Health, Bury PCT
Dr Andrew Fowell	Macmillan Consultant in Palliative Medicine, Bodfan Eryri Hospital, Caernarvon
Mr Mark Gilmore	Lead Nurse, North West Midlands Cancer Network
Ms Julie Gorry	Chief Executive, Willowbrook Hospice, Merseyside
Dr Jane Halpin	Lead Clinician, Mount Vernon Cancer Network

Ms Liz Holford	Assistant Director – Workforce Strategy (Acute), North East London Education and Workforce Confederation
Ms Katherine Hopkins	Lead Nurse for Palliative Care, The Royal Free Hospital, London
Mr Liam Hughes	Chief Executive, East Leeds PCT
Mr Patrick Keane	Head of Strategy, Policy and Planning, Northumberland, Tyne and Wear SHA
Mr Kevin Keogh	Centre Manager, Marie Curie Centre, Edenhall, London
Mr Mark Lyles	Cancer Lead, Bradford City PCT
Dr Chantal Meystre	Clinical Director, Myton Hamlet Hospice, Warwick
Mr David Oliviere	Director of Education, St Christopher's Hospice, London
Ms Joanna Paul	General Manager: Medical Directorate and Lead Cancer Manager, St Mary's Hospital, London
Prof. Malcolm Payne	Director of Psychosocial and Spiritual Care, St Christopher's Hospice
Mrs Judith Powell	Matron, Wakefield Hospice
Dr Cliff Richards	Primary Care Cancer Lead, Runcorn, Cheshire
Mr Steve Richards	Head of Service Development, Macmillan Cancer Relief
Dr Richard Scheffer	Medical Director/Consultant in Palliative Medicine, Rowcroft Hospice, Torquay
Dr Greg Tanner	General Practitioner, Bridgwater, Somerset
Mr Peter Tebbitt	National Palliative Care Development Adviser, National Council for Hospice and Specialist Palliative Care
Dr Adrian Tookman	Lead Clinician, North London Supportive and Palliative Care Network
Dr Julia Verne	Consultant in Public Health Medicine, Government Office for the South and West

The Commissioner and Provider Reference Group was facilitated by Ms Susan O'Toole, Consultant in Health Policy and Management, supported by Mrs Valerie Saunders, Manager, Northern and Yorkshire Cancer Registry and Information Service.

## Appendix 2.5

# Membership of the Allied Health Professionals Reference Group

A2

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## Appendix 2.6

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## Appendix 3

# Glossary

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### **‘Burn-out’**

Recognised signs of distress in health and social care professionals as a result of excessive workplace demands that lead to feelings of disappointment in self, exhaustion and lack of confidence. Demoralisation may develop, causing lack of engagement and, ultimately, withdrawal from the workplace.

### **Caldicott Guardians**

Appointed within each NHS organisation to oversee how staff use personal health information and to ensure that patients’ rights to confidentiality are respected.

### **Cancer Networks**

Working across organisational boundaries, Cancer Networks bring together organisations and service users to work closely together in partnership to plan and co-ordinate services in line with national guidance and to improve and monitor local service delivery. See wider definition in Box 1.1, page 37.

### **Cancer Research Networks**

See **National Cancer Research Network**.

### **Cancer Services Collaborative ‘Improvement Partnerships’**

A national NHS programme, supported by Service Improvement Teams, to improve access to and quality of patient services. It is designed to improve experience and outcomes for patients with suspected or diagnosed cancer across the patient pathway.

### **Cancer Services Co-ordinating Group**

Body responsible for producing the all-Wales Minimum Standards For Specialist Palliative Care (to become the all-Wales Minimum Standards for Cancer from March 2004). Have also produced a strategic development plan that outlines current and future developments facing cancer services in Wales.

### **Care homes**

Community-based provision in the statutory, voluntary and independent sectors offering a range of short-term and long-term accommodation and care to adults with a variety of needs.

## **Care Standards Inspectorate for Wales**

Established in April 2001 under the Care Standards Act 2000 as the regulator for social and health care in Wales.

## **Clinical supervision**

Practice-focused professional relationship that enables practitioners to reflect on their practice with the support of a skilled supervisor.

## **Coalition for Cancer Information**

Established on the recommendation of the Cancer Information Advisory Group, bringing together groups of charities, the Department of Health, Cancer Services Collaborative and NHS Direct Online to oversee the development, dissemination and delivery of high quality information to patients.

## **Commissioners**

Organisations responsible for commissioning health care services for populations. In England, Primary Care Organisations; in Wales, Local Health Boards and Health Commission Wales (specialist services).

## **Compact**

The Compact between government and the voluntary and community sector was launched in November 1998. The Compact sets out the principles and undertakings that should underpin relationships between the voluntary and community sector and government, and is considered integral to increasing the involvement of patients and the public in health.

## **Expert Patients Programme**

Series of programmes dedicated to developing patients' confidence and motivation to use their own skills and knowledge to manage chronic illness, such as cancer.

## **Fair Access to Care Services**

Provides councils with a framework for setting their eligibility criteria for adult social care.

## **General palliative care**

Services in all sectors providing day-to-day care to patients with advanced cancer and their carers, designed to alleviate symptoms and concerns, but not expected to cure the cancer.

## **Generalists**

See **Health and social care professionals providing day-to-day care to patients and carers**

### **Health and social care professionals providing day-to-day care to patients and carers**

Refers to professionals who provide usual care to the person with cancer and their family as an integral part of routine practice, whatever the location. For some groups of professionals, such as general practitioners and district nurses, people with cancer will not be the sole focus of their work.

### **‘Key worker’**

Person who, with the patient’s consent and agreement, takes a key role in co-ordinating the patient’s care and promoting continuity, ensuring the patient knows who to access for information and advice.

### **Local Health Alliances**

Established in Wales as a means of bringing together local authority and health authority personnel with representatives from local health groups, community voluntary organisations and community health councils to address health issues of importance to local communities.

### **Multidisciplinary teams**

A group of health and social care professionals from a range of disciplines who meet regularly to discuss and agree plans of treatment and care for people with a particular type of cancer or problem, or in a particular location. Includes primary care teams, site-specific cancer teams, therapy teams and specialist palliative care teams.

### **National Cancer Research Institute**

Partnership of the major cancer research funding bodies from the Department of Health, Medical Research Council and all major charities involved in cancer research. Takes a strategic oversight of cancer research in the UK, identifying gaps and opportunities in current research and facilitating collaboration between funding bodies.

### **National Cancer Research Network**

Established by the Department of Health in April 2001 to provide the NHS with an infrastructure to support research into cancer treatments and support research undertaken by cancer charities. It aims to improve the speed, quality and integration of research. Has created Cancer Research Networks, closely aligned to Cancer Networks, throughout England.

### **National Care Standards Commission**

Independent public body set up under the Care Standards Act 2000 to regulate social care and private and voluntary health care services throughout England. In April 2004, its health care functions will be taken up by the Commission for Healthcare Audit (CHAI) and social care functions by the new Commission for Social Care Inspection (CSCI).

### **National Electronic Library for Health**

On-line resource of the NHS Information Authority working with NHS libraries to develop a digital library for NHS staff, patients and the public.

### **National Partnership Group**

Group drawn from the NHS and voluntary sector and chaired by the National Cancer Director. Tasked with developing proposals for a new approach to specialist palliative care planning and funding.

### **New Opportunities Fund**

National Lottery fund distributor created in 1998 to award grants to education, health and environment projects throughout the UK.

### **Normal working hours**

09.00-17.00, Monday-Friday.

### **Palliative care**

Active holistic care of patients with advanced progressive illness, focusing on management of pain and other symptoms and provision of psychological, social and spiritual support. See fuller definition on page 20.

### **Partnership Groups**

Bring together patients, carers and professionals to ensure the views of users are taken into account in the development of services.

### **Patient Advice and Liaison Services (PALS)**

Set up within NHS organisations in England to advise, support and provide information to patients, PALS liaise with staff, managers and others in pursuing patient concerns about services and negotiate immediate changes to the way services are delivered.

### **Patient and Public Involvement**

The Department of Health set up the Commission for Patient and Public Involvement in January 2003 as an independent, non-departmental public body aiming to ensure that the public is involved in decision making about health and health services.

### **Patient Forums**

Introduced to England's acute NHS Trusts and Primary Care Organisations during 2003, Patient Forums are made up of local people who represent the views of local communities on the quality and configuration of health services.

### **Patient pathway**

A term used to denote the phases patients who are living with the consequences of cancer pass through, from the time they first suspect something might be wrong to beyond the end of treatment. It is dynamic and can be somewhat unpredictable. For some, the pathway will also include the time when cancer recurs and that leading up to the death of the patient. See Figure I.1, page 19.

### **Peer review**

A process of independent review of services undertaken to ensure they are safe and effective and comply with national cancer standards. The exercise is undertaken with the overall aim of improving care for people with cancer and their families. Reviewers come from a different NHS Trust/Cancer Network from the one visited, but may not necessarily come from the same discipline as the service being reviewed.

### **People with sensory impairment**

Refers to people who, because of impairment in hearing, sight, speech, touch or cognition, may have difficulty communicating.

### **Primary care**

Services provided in community settings outside secondary care (including GP services, general dental, ophthalmic, mental health, learning disability and pharmaceutical services and community health and health promotion) with which patients usually have first contact (see also **Secondary Care** and **Tertiary Care**).

### **Primary Care Organisations**

Statutory bodies in England responsible for commissioning all health services and providing some services on behalf of local populations.

### **Professionals**

Within the context of this Guidance, 'professionals' refers to health and social care professionals working with people with cancer and their families in any setting, either generalist or specialist.

### **Provider organisations**

Organisations within the statutory, independent and voluntary sectors who employ staff to provide health and social care services to people with cancer and their families.

### **Secondary care**

Services provided (usually in hospital) by multidisciplinary teams following initial diagnosis and/or treatment in primary care settings, such as a GP service (see also **Primary Care** and **Tertiary Care**).

### **Self help**

The process of patients and carers using their own resources and abilities to manage their cancer.

### **Service directories**

Set up by Cancer Networks to provide patients and staff with information on cancer-related resources available locally and nationally.

### **Service model**

Describes the principles of how a service is organised for patients with either a particular cancer or specific problems and concerns that arise as a result of the disease and its treatment. The service model specifies the features of how the service is configured and delivered.

### **Service user**

Person accessing supportive and palliative care services from any sector.

### **Social Care Institute for Excellence (SCIE)**

Funded by the Department of Health and Welsh Assembly Government, SCIE gathers and publicises knowledge about how to make social care services better. Its function is similar to that of the National Institute for Clinical Excellence in health care.

### **Specialist palliative care**

Services in all sectors that specialise in palliative care and which include consultants in palliative medicine, clinical nurse specialists in palliative care and a range of other specialist expertise.

### **Statutory sector**

Services in health and social care established in statute and funded by the state.

### **Supportive care**

Care that helps people with cancer and their families to cope with cancer and its treatment throughout the patient pathway. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. See fuller definition on page 18.

### **Supportive and Palliative Care Co-ordinating Group**

Supports the National Cancer Director in establishing a comprehensive supportive and palliative care strategy to improve the experience of care for those affected by cancer by ensuring coherence between strands of work and between agencies.

### **Survivorship**

Concept derived from USA which addresses the complex physical, social, psychological and spiritual needs of people who have successfully come through cancer treatment programmes.

### **Tertiary care**

Services provided by specialised units who have access to expertise and technology generally not available in primary and secondary care settings for the treatment and management of patients with unusual or complex disorders (see also **Primary Care** and **Secondary Care**).

### **Voluntary sector**

Not for profit autonomous organisations involved in the delivery of health or social care services to people with cancer and their carers and in commissioning research into cancer treatments and causes. These can range from small local self-help and support groups to the largest and most sophisticated charities, such as Cancer Research UK and Macmillan Cancer Relief.

### **Wales Cancer Trials Network**

Set up in April 1998 as a jointly funded collaboration between the Cancer Research Campaign (now Cancer Research UK) and the Welsh Assembly Government to support NHS cancer teams in Wales to take part in research aimed at improving treatments for patients with cancer.

### **Workforce Development Confederations**

Established by the Department of Health in April 2001 to drive forward programmes for creating an integrated approach at local level to developing the workforce needs of the health and social care sector.

### **Workforce Development Steering Group**

All-Wales group responsible for planning the NHS workforce in terms of numbers, skill mix and job design, and commissioning education and training.



Retired: This guidance is retired which means it has no status and the health and care system is not expected to follow it.

