

# **Guidance on Cancer Services**

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

### **Manual**

**Draft**

**Second consultation version, September 2002**

# **Contents**

**1. Introduction**

**2. Background**

**3. Co-ordination of care**

**4. Face-to-face communication**

**5. Information**

**6. Psychological support services**

**7. Specialist palliative care services**

**8. General palliative care services**

**Appendix 1 – How the Guidance was produced**

**Appendix 2 – Membership of Editorial Board**

**Appendix 3 – Focus group – service user membership**

**Appendix 4 – Participants in the supportive and palliative care proposal-generating event**

**Appendix 5 – Referees of the supportive and palliative care proposals**

**Appendix 6 – Guidance development team**

**Appendix 7 – Focus groups – commissioner membership**

**Appendix 8 – Evidence review team**

# 1. Introduction

## A. Context

1.1 This manual is designed to guide commissioning, planning and development of supportive and palliative care services. The primary audience for the Guidance is NHS commissioners of supportive and palliative care services (across health and social care sectors), whether supplied directly or by non-NHS providers on behalf of the NHS. It follows on from the Calman-Hine report, *A Policy Framework for Commissioning Cancer Services* (1), *The NHS Cancer Plan* (2), and the Cameron Report, *Cancer Services in Wales: a report by the Cancer Services Expert Group* (3).

1.2 *Shifting the Balance of Power: The Next Steps* (4) and *Improving Health in Wales* (5) 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.

1.3 The Guidance forms a key element of the Supportive Care Strategy for England and is one part of a series of initiatives designed to improve the experience of care of patients with cancer and their carers. These initiatives include:

- the development of a Supportive and Palliative Care Co-ordinating Group for England
- the establishment of the Coalition for Cancer Information
- the User Involvement Strategy, which has led to a project run jointly by the Department of Health and Macmillan Cancer Relief to support user involvement in every cancer network
- the New Opportunities Fund *Living with Cancer* initiative
- Cancer Services Collaborative initiatives focused on improving the patients' care experience and the community palliative care Gold Standards programme
- the development of draft National Standards for Specialist Palliative Care for Cancer Services
- a Department of Health-funded initiative on education and support for district and community nurses in every cancer network on the principles and practice of palliative care.

1.4 In Wales, similar initiatives are running, including:

- the establishment of the Wales Association of Palliative Care
- the development of a strategy for palliative care services in Wales
- the All-Wales Minimum Standards for Specialist Palliative Care (6)
- a Cancer Information Framework and the establishment of a Cancer Information Framework Project Board to oversee its implementation (7).

1.5 The Guidance draws together strands of work undertaken for a number of these initiatives. The sources have been clearly referenced within the document and, where indicated, have been used to formulate recommendations.

1.6 It also reflects the outcomes of the Kennedy Inquiry (8), which set out a number of recommendations in relation to communication skills for healthcare professionals, and draws on the Commission for Health Improvement/Audit Commission report on cancer services (9) and the National Cancer Patient Survey in England (10), both of which clearly identify issues that require urgent review and action.

## **B. Aims and scope**

1.7 The purpose of the Guidance is to identify service models most likely to lead to high quality care and services for all people with cancer and their carers. It describes organisational and professional interventions for the differing service components that make up supportive and palliative care, underpinned by effective co-ordination.

1.8 The following topic areas are covered:

- Co-ordination of care
- Face-to-face communication
- Information
- Psychological support services
- Specialist palliative care services
- General palliative care services
- Social support services
- Rehabilitation services
- Complementary therapy services
- Spiritual support services
- Carer and bereavement support services
- User involvement.

1.9 The Guidance complements the site-specific cancer *Improving Outcomes* manuals, but does not review the effectiveness of technologies such as pharmacological and non-pharmacological interventions to control symptoms. While the site-specific manuals focus on services required for patients with specific cancers, this Guidance reflects the common components of effective supportive and palliative care for *all* people with cancer and their carers. The scope of the Guidance is shown in Box 1.1.

### **Box 1.1 Scope of the Guidance**

- The primary audience is those who will commission supportive and palliative care services from both the statutory and voluntary sectors, and health and social care sectors, using NHS resources.
- The Guidance relates to services commissioned in England and Wales, and covers all settings in which care may be delivered.
- While it focuses on commissioning services for patients with cancer and their carers,

it is anticipated that the Guidance may inform the development of effective service models for other groups of patients with similar needs.

- The primary focus is on commissioning services for adults, but the needs of children who may be affected by an adult carer or relative with cancer are also acknowledged.

### **C. How the Guidance was produced**

1.10 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. A wide range of individuals representing service users, professionals and policy-makers were involved in generating proposals for recommendations which were then critically appraised in the light of research evidence. The material was then synthesised and refined, taking account of the resource implications.

1.11 The first stage of the production process for the Guidance took place at a two-day event at which a large group of relevant healthcare professionals, people with personal experience of cancer, healthcare commissioners and academics from around the country met to put forward structured proposals based on their experience and knowledge of the research literature. These proposals were sent to referees, including clinicians, academics, representatives of health authorities, the Department of Health, patient organisations and relevant charities, many of whom made detailed comments and suggestions. Systematic reviews of the research literature were then carried out by the Department of Palliative Care and Policy, King's College, London.

1.12 This process culminated in the production of two large sources of information, one with a practical or operational focus, and the other containing detailed research evidence on effectiveness. The Guidance draws on both of these sources, with added input from commissioners, people with cancer, carers and experts in the particular fields who gave advice. It was written by the Guidance Development Team, with input from the Editorial Board, and was informed by focus groups of commissioners and service-users.

1.13 A summary of the processes used to collate the Guidance is given in Appendix 1.

### **D. The organisation of the Guidance**

1.14 From the perspective of patients and carers, the topic areas reflected in this Guidance form part of a package of care which, if comprehensive, will meet their needs. Many aspects are delivered simultaneously by one or more health and social care professionals aligned with a particular service, and may be provided at different times within patients' overall experience of care.

1.15 For the practical purposes of producing the Guidance, however, we have had to present the components of services developed to meet the overall care needs of patients in separate sections, albeit with areas of significant overlap. While this satisfies the need to produce a coherent and logical document, we accept that it does not accurately reflect the actual day-to-day needs and experience of care of people with cancer. The key

components of services are, however, defined to a degree sufficient to describe a competent and effective supportive and palliative care service.

1.16 The Guidance is divided into two sources: a Guidance Manual, and the Research Evidence. The topic areas are discussed in the same order for ease of cross-reference. The order is intended to represent a logical sequence of issues, and does not reflect priorities.

1.17 The first source (The Guidance Manual) is based on all available sources of information. Each topic area chapter (with the exception of Chapter 3, *Co-ordination of Care*) is organised in the same manner:

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

**Objectives.** A short statement of what we are trying to achieve for patients and carers.

**Recommendations.** Presented in three sections:

- *Overview:* an overview of how services will need to be organised to achieve the objectives.
- *Service configuration and delivery:* specific recommendations about the service model and the processes required to achieve the objectives.
- *Workforce development:* covers the education, training and support requirements staff will need to deliver services.

**Evidence.** Sets out the evidence supporting the recommendations. To ensure the Guidance is anchored in evidence, the research literature was reviewed and critically appraised. The reliability and quality of evidence supporting the recommendations is graded from A-C (11) throughout the document, as shown in Table 1.1.

<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.

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).

The grades refer to the nature of the evidence, not the strength of the recommendations. It should be stressed that the quality of research evidence forms a continuum. It has been categorised here for convenience, but there is overlap between categories. A summary of

the processes used to identify the types of evidence is given in Appendix 1. *(At this stage of preparation of the Guidance, some additional evidence, not yet incorporated into the evidence review tables, has been explicitly referred to in the text. This evidence, mainly of type B-C, is clearly referenced and marked as 'pending confirmation from the evidence review team'. In the final guidance document, the evidence section will not contain references to individual studies.)*

**Measurement**\*. Presents ways in which the structure, processes and outcomes of care delivery can be monitored.

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

1.18 The second source (The Research Evidence) is a condensed version of systematic reviews of research used to inform the Guidance and is published in electronic format [website address to come and to be confirmed whether will appear as CD-ROM]. It includes tables with information about individual studies and is fully referenced. This source includes the final report of the commissioned costing work [to come...].

1.19 The final recommendations will also be available in a version for the public.

## **E. Implementation**

1.20 The recommendations identified in the Guidance represent a set of priorities in areas most likely to make a difference to patients in relation to supportive and palliative care. The resource implications of implementing the recommendations are considered. Many may have been implemented already in some areas, and some incorporate recommendations generated by other sources, such as the Cancer Information Advisory Group in England.

1.21 The process of developing the recommendations was underpinned by a framework depicting levels of service operation (Box 1.2). While the recommendations are not presented in the Guidance under these headings, the framework gave the Guidance developers defined reference points and a coherent structure from which to formulate the recommendations.

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\* The *Measurement* and *Resource implications* sections have not been included in this draft of the Guidance Manual. They will be included when Part A and Part B are amalgamated, subject to a final round of consultation.

**Box 1.2 Framework of levels of service operation used to underpin formulation of recommendations**

- National level
- Cancer network level
- Provider organisation level
- Team level
- Patient level

1.22 It is not anticipated that all the recommendations will be achieved in all areas immediately, or in the short term. Some may be relatively straightforward to implement, while others will be goals at which to aim. Strategic Health Authorities (SHAs), Primary Care Trusts (PCTs), local health boards, cancer networks and voluntary organisations will need to identify which to prioritise, taking into account the quality and configuration of existing local services and the resources available. It might seem reasonable to prioritise on the basis of the likely impact of change – as far as this may be judged from the evidence – but this, too, depends on the degree to which the current service model differs from that which is recommended. As many of the recommendations relate to workforce development, close involvement of Workforce Development Confederations in England will be needed to ensure that high quality training programmes are available to deliver (over time) the necessary increases in human resources and skills.

1.23 The topic areas vary widely, and the evidence suggests that change in some areas will have more impact than change in others. The amount and strength of supporting evidence available also varies, partly reflecting the fact that research into supportive and palliative care has tended to focus on specific issues. At various parts in the Guidance, suggestions have been made on some of the ways in which commissioners and providers might consider addressing a particular recommendation. No directly applicable research evidence exists for a number of these, but they draw on the clinical experience of the Editorial Board established to support the Guidance development and other experts who have contributed to the consultation process.

1.24 Local circumstances will dictate modifications in the way the Guidance is implemented, and cancer networks (in collaboration with users and providers of services) should be leading the discussions about the configuration of local services and the nature of care to be provided. In England, PCTs need to be fully engaged in this process, and PCT lead clinicians for cancer are likely to play a key role.

1.25 Standards will emerge from the recommendations to become part of the *Manual of Cancer Services Standards* in England and the All-Wales Minimum Standards for Specialist Palliative Care. It is anticipated that these standards will form the foundation for a variety of processes aimed at assessing the quality of care provided across a cancer network. Individual service providers will wish to audit the quality of care they are providing, while SHAs/health boards and cancer networks will wish to assess the quality of the range of services provided and commissioned.



1.26 Unanswered questions and areas of uncertainty remain. Some of these are being studied in high-quality research, in which all commissioners and providers should be encouraged to participate in order to contribute to improvements in knowledge about the best models for supportive and palliative care services. There are many areas which require further investigation, however; in particular, comparisons of different models or ways of providing interventions and measuring outcomes important to patients and carers are necessary.

1.27 It is anticipated that the Guidance will be useful in determining the priorities for the research agenda for supportive and palliative care. The National Cancer Research Institute in England, with the formation of a number of clinical studies development groups which have direct relevance to this area of knowledge development (palliative care and primary care oncology, for example), might act as a vehicle through which to develop relevant portfolios of studies.

### References

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## 2. Background

2.1 More than one in three people in England and Wales will develop cancer at some stage of their lives. Every year, over 200,000 people are diagnosed with cancer in England and Wales, with 120,000 deaths – approximately 25% of all deaths in UK. More than 1,000,000 people in the UK at any one time will be living with cancer. [these figures awaiting confirmation...]

2.2 All people with cancer and their carers will have needs in relation to supportive and palliative care at all stages of the illness, from pre-diagnosis onwards. Most of the care they receive will be delivered by their usual health and social care providers in primary or secondary settings. Some people will require access to specialist services.

### A. Definitions of supportive and palliative care

2.3 The understandings of supportive and palliative care on which this Guidance is based lean heavily on work by the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS), and the Guidance endorses a number of their recommendations on definitions of the different forms of care people with cancer and carers receive.

#### Supportive care

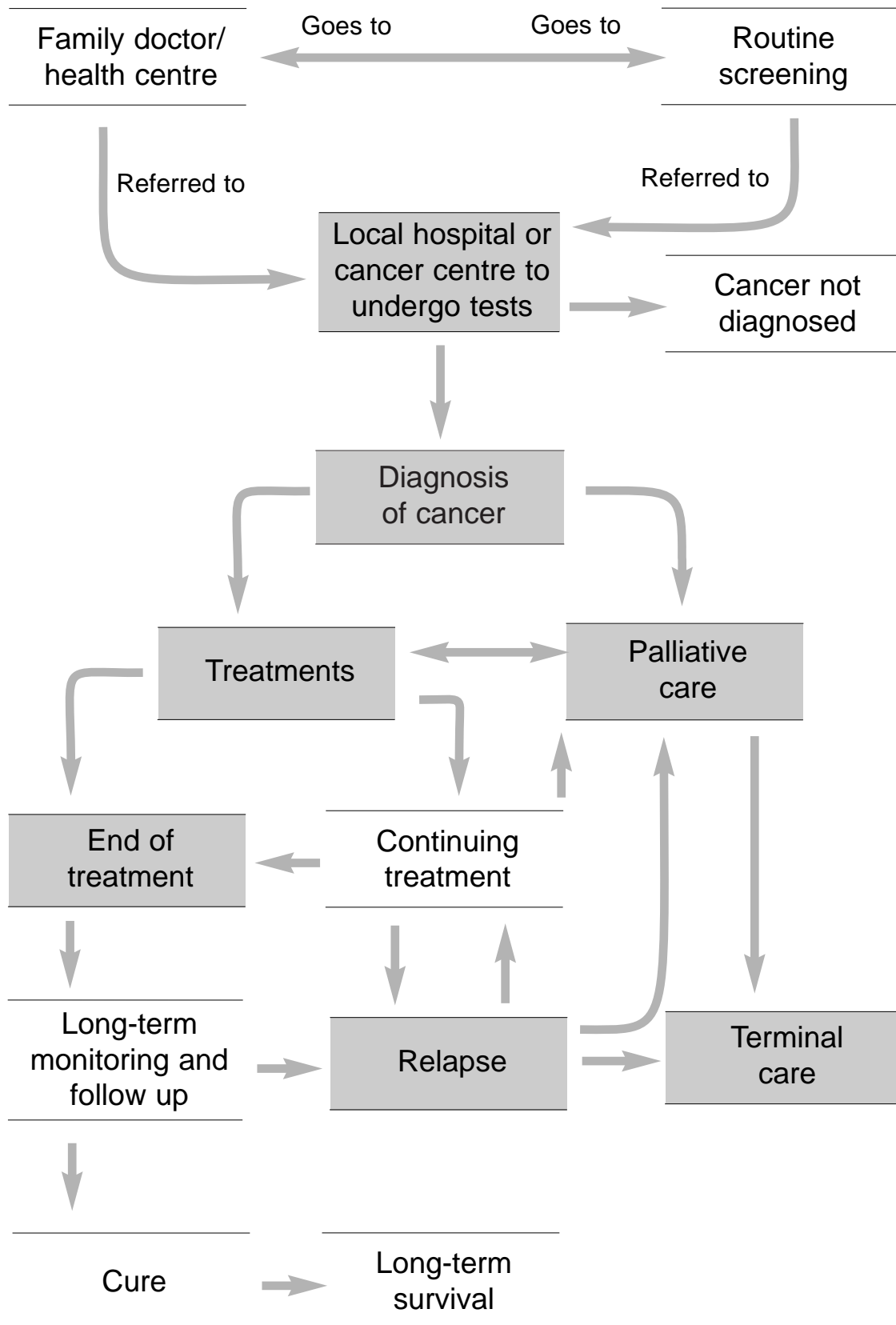
2.4 The NCHSPCS has suggested the following working definition of **supportive care**. It is described as care that:

‘...helps the patient and their family to cope with cancer and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. 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’ (1).

2.5 Supportive care is provided to people with cancer and their carers throughout the patient pathway (*please refer to appended Figure – name ‘Figure 2.1’*). It should not only be given equal priority with other aspects of care, but should also 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.

# Map of patient pathway †



■ Key points in the cancer journey

† Supportive care is provided at all stages of the pathway from pre diagnosis onwards

2.6 Supportive care is an ‘umbrella’ term for all the services, generalist and specialist, that may be required to support people with cancer and their carers. It is not stage-of-disease dependent, and reflects the fact that people have supportive care needs from the time that the possibility of cancer is first raised.

2.7 Supportive care is not a distinct specialty but is the responsibility of all health and social care professionals, who deliver care that is informed and driven by theories, models and frameworks drawn from diverse sources. It is underpinned by open and sensitive communication and by organisations and teams who work in a co-ordinated way to ensure the smooth progression of patients from one service to another.

### **Palliative care**

2.8 The NCHSPCS has offered the following definition of **palliative care**, based on The World Health Organization’s definition (2). 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’ (1).

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

- affirm life, and regard dying as a natural process
- provide relief from pain and other symptoms
- integrate psychological and spiritual aspects of care
- offer a support system to help patients to live as actively as possible until death
- offer a support system to help the family cope during the patient’s illness and in their own environment (2).

2.10 This definition and the principles on which it is based will evolve over time. It is now widely recognised that palliative care has a crucial role in the total care received by the patient and carers at a variety of points throughout the course of the disease from diagnosis to end-of-life care, delivered in conjunction with anti-cancer and other treatments (3). It tends to be associated in patients’ and carers’ perceptions, however, with care provided to dying people (4); this has significant implications for acceptability and access.

2.11 Palliative care, like supportive care, is the responsibility of all health and social care professionals, and is delivered by two distinct categories of staff:

- the patient and carers’ usual professional carers
- professionals who specialise in palliative care, some of whom are accredited specialists (consultants in palliative medicine and clinical nurse specialists in palliative care, for example) (1).

2.12 Palliative care encompasses many of the elements identified as ‘supportive care’, and the principles on which they are based are broadly similar. There are, however, well-defined areas of expertise within specialist palliative care to which the patient and carer may need access, such as interventions to deal with:

- unresolved symptoms
- complex end-of-life issues
- complex bereavement issues
- complex psychosocial issues.

### **B. Supportive and palliative care services**

2.13 Supportive and palliative care services for those affected by cancer are provided by a wide range of health and social care professionals with whom patients and carers come into contact. Each is provided as an essential part of care and service delivery from diagnosis to death. They are designed to meet the needs of patients with cancer and their carers and should be delivered where patients and carers need them or want them – in the community (which includes not only the patient’s home but also care homes), in hospital, or in a hospice (5).

2.14 Various providers are involved in delivering some or all of these services, including services in primary care, secondary care and the voluntary and social sectors. In addition, patients and carers draw significant support from friends, family, support groups, volunteers, therapists, and other community based non-statutory resources.

2.15 Providing supportive and palliative care should be an integral part of every health and social care professional's role, but for most, the provision of support for people with cancer forms only a small part of their workload. It is relatively straightforward to categorise some groups of healthcare professionals as 'generalists' in the field (general practitioners (GPs) and district nurses, for example), while others are specialists who may have received additional training and qualifications in one or more aspects of supportive and palliative care and acquired substantial practical experience. These specialists frequently dedicate all or most of their time to the care of people with cancer. Examples of specialists in supportive and/or palliative care would include:

- site-specific nurse specialists
- cancer counsellors
- cancer information nurses/other professionals
- specialist allied health professionals
- physicians in palliative medicine and palliative care nurse specialists.

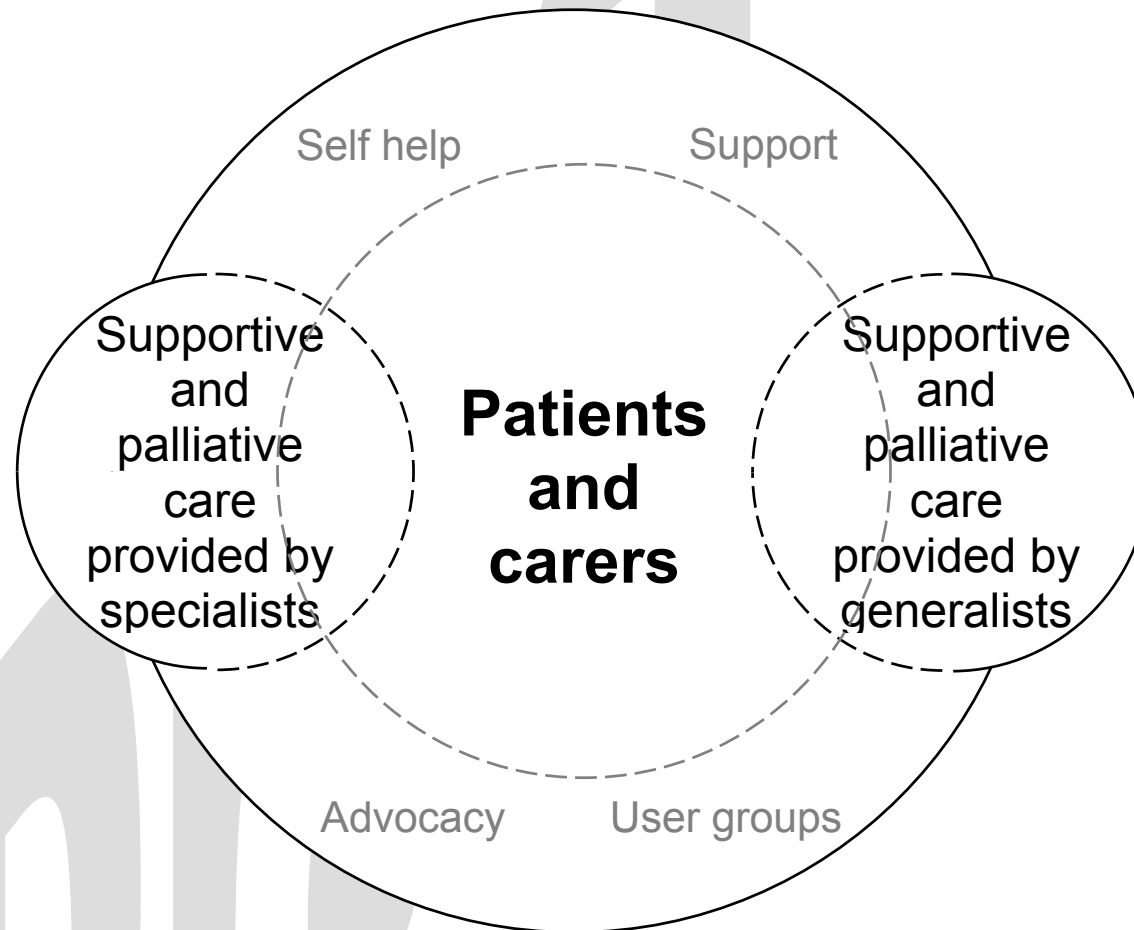
2.16 For others, their ‘generalist’ or ‘specialist’ status will depend on the circumstances in which they work. A social worker with a local authority, for example, may be a generalist working with a wide range of clients, while a social worker employed by a hospice will be working as a specialist in palliative care.

2.17 Figure 2.2 depicts the relative contributions of those involved in supportive and palliative care. It demonstrates the central role patients and carers play in their own care and in making decisions about the care they receive. Their central role emphasises the knowledge and experience they bring and the importance of user empowerment as a key principle underpinning good supportive and palliative care.

2.18 Alongside professional health and social care services, self help and support play vital roles in helping people to gain strength through shared experience and informal information exchange, and in giving them the chance to feel more in control. Self-help and support groups and other advocate services are important in supporting and empowering patients, enabling them to identify and meet their needs.

2.19 Figure 2.2 shows how patients and families receive advocacy services and support from their usual professional carers who provide general supportive and palliative care. Specialist services also fulfil this function at different times in the patient and carer experience. The broken lines in Figure 2.2 reflect flexibility, movement and the potential to change during each patient's or carer's cancer experience, and emphasise how the patient pathway tends to fluctuate according to individual need. The relative contributions of those involved in supportive and palliative care, including patients and carers, are consequently liable to change also.

**Figure 2.2 Supportive and palliative care: contribution of patients and carers, generalists and specialists**



### **C. Re-modelling supportive and palliative care services**

2.20 The diagnosis and treatment of cancer have profound effects on the quality of life of patients and carers. In addition to symptoms associated with the disease and its treatment, uncertainty and emotional distress are common.

2.21 Service providers have a responsibility to support people with cancer and their families through these experiences, but many patients report that the services they receive do not deliver what they want (4, 6).

### **D. What do patients and carers want from services?**

2.22 As part of the process of developing a Supportive Care Strategy for Cancer Patients in England, Cancerlink undertook a questionnaire survey involving people in England and Wales and held a meeting of expert patients and carers (7). Results from these exercises highlighted the following domains as the key components of good supportive care for patients and carers:

- **Being treated as a human being.** People want to be treated as individuals, with dignity, and with respect for culture, lifestyles and beliefs.
- **Empowerment.** The ability to have their voice heard, to be valued for their knowledge and skills, and to exercise real choice about treatments and services are central to patients' and carers' wishes.
- **Information.** Patients and carers should receive all the information they want about their condition and possible treatment. It should be given in an honest, timely and sensitive manner.
- **Having choices.** Patients and carers want to know what options are available to them from the NHS, voluntary and private sectors, including access to self-help and support groups, complementary therapy services, and information.
- **Continuity of care.** Good communication and co-ordination of services between health and social care professionals working across the NHS and social sectors is essential.
- **Equal access.** People want access to services of comparable quality wherever they are delivered.
- **Meeting physical needs.** Physical symptoms should be managed to a degree that is acceptable to patients and achievable in relation to the clinical situation and current knowledge and expertise.
- **Meeting psychological needs.** Patients and carers need emotional support from professionals who are prepared to listen to them and are capable of understanding their concerns.
- **Meeting social needs.** Support for carers, advice on financial and employment issues and provision of transport are necessary.
- **Meeting spiritual needs.** Patients and carers want support to help them explore the spiritual issues important to them.



2.23 A survey by the Commission for Health Improvement/Audit Commission (4) revealed similar findings on the wishes and needs of people in England and Wales. In addition, it indicated that patients want to:

- have access to high quality information materials in a variety of media, such as leaflets, booklets, videos, and the World Wide Web (Internet)
- undergo only those interventions for which they have given informed consent
- die in the place of their choice, if possible
- be assured that their carers will be supported throughout the illness and in bereavement.

#### **E. Current service provision**

2.24 Many providers of supportive and palliative care in the public, voluntary and private sectors are offering highly effective services geared towards meeting people's needs, and there are well-documented areas of excellence throughout England and Wales (4).

2.25 There are, however, reports of deficiencies in service provision that are having effects on patient care. Many of the problems relate to specific areas of treatment. Long delays between diagnosis and commencement of treatment, inadequate facilities and inconsistencies in approach between different health and social care professionals are among them. But disappointment with support throughout illness episodes also figures large as a cause of patient and carer dissatisfaction. These concerns have been echoed strongly in work being undertaken as part of the Cancer Services Collaborative, which aims to improve the experience of people with cancer and carers by involving them in the process of identifying core issues and developing local solutions.

2.26 Practitioners are also seeing deficiencies in services. As part of the work of assembling this Guidance, members of the Editorial Board were invited to provide succinct summaries of their perceptions of the current situation in key service areas. Among the issues they reported were:

- patchy, inconsistent access to high quality cancer information
- varied and inequitable access to rehabilitation services, with few patients being able to receive services from the wide range of health and social care professionals necessary to ensure their needs are met appropriately
- limited availability of people with the necessary qualities and experience to provide spiritual support
- variable provision of bereavement support services in NHS Trusts
- insufficient numbers of psychological care specialists who have specific training or experience in working with people with cancer, and insufficient resources to support them
- variability in the provision of specialist palliative care services throughout England and Wales, both in relation to the number of available specialist palliative care beds and to the establishment of fully functioning multi-professional specialist palliative care teams in acute hospitals and the community. This observation is supported by the

findings of a survey undertaken by the NCHSPCS on behalf of the Department of Health in 1999 (8).

- continuing organisational and funding barriers between health and social care services (despite recent legislation), meaning that integration of services for patients and carers tends to be dependent on the goodwill and flexibility of particular individuals in different services. The different cultures of health and social care can contribute to this lack of integration.

2.27 A large-scale survey of patients with cancer has recently been undertaken in England (9). The survey assessed the experience of care provided in NHS Trusts among patients who attended hospital in 1999-2000. People with breast, colorectal, lung, prostate and ovarian cancer and non-Hodgkin's lymphoma were invited to participate. Each patient was sent a 20-page questionnaire asking about their experience of care in relation to many of the topics identified above. Over 65,000 patients responded, giving a response rate of 74%.

2.28 Many patients who took part in the survey reported positively on their experience of care. For example:

- eighty-six per cent reported confidence in all of their doctors
- seventy-nine per cent reported that they were always treated with dignity and respect
- eighty-nine per cent felt sufficiently involved in decision making about their treatment/care.

2.29 On many items raised in the survey, however, wide variations were observed between the best and the worst Trusts across the country, demonstrating the scope for improvement. There were also variations in the views of patients with different tumour types: for instance, in general, breast cancer patients reported better experience of care than others.

2.30 The survey also highlighted inadequacies in care provision. Some of the key findings are shown below.

#### **Respect and dignity**

- Fourteen per cent of respondents reported that hospital staff had discussed their case in front of them 'as though they were not there' (breast cancer, 11%; other cancers, 16%). In the worst case, 38% of patients with colorectal cancer at one Trust reported this.

#### **Written information**

- Only 38% of respondents had been given written or printed information about their treatment or condition at the time of diagnosis (breast cancer, 51%; other cancers, 29%).

### **Communication**

- Only two thirds (66%) of patients said that they completely understood the different types of treatment available for their condition.
- Thirteen per cent believed that on at least one occasion during their first hospital treatment, doctors or nurses were deliberately withholding information from them.
- Sixteen per cent of patients could not understand doctors' answers to their questions all or most of the time. The equivalent figure for nurses' answers to questions was 18%.
- Twenty-nine per cent said they had not completely understood discussions of the possible side effects of their treatment.

### **Discharge/rehabilitation**

- Twenty-five per cent of patients had either been given no explanation of the time needed to resume normal activities, or an unclear explanation (breast cancer, 21%; all other cancers, 27%).

### **Support and self-help groups**

- Whether patients were told about a support or self-help group varied markedly according to the type of cancer they had. Two thirds (68%) of women with breast cancer were given this information, compared with fewer than half (44%) of other patients and less than a third of men with prostate cancer.

2.31 The survey found that in general, women were more critical about the quality of care they received than men. Similarly, younger patients tended to be more critical of care than those aged over 65 years.

2.32 People from ethnic minority backgrounds, while only a very small proportion of the sample, were more likely than average to report unfavourably about their experiences of cancer care, with problems associated with understanding explanations, having confidence and trust in doctors and nurses and being treated with respect and dignity among those reported.

### **F. How can services be improved to meet the needs of patients and carers?**

2.33 Patients and carers are especially concerned that their views on the shape and delivery of services are not being taken into account. They want to feel in control of their care, rather than being frustrated onlookers. Yet less than half of Health Authorities in England involved in the Commission for Health Improvement /Audit Commission survey in 2000 reported that patients (either as individuals or through representative groups or community health councils) had 'some say' in planning services, and few of the cancer network management boards in England at that time included community representatives (4).

2.34 Services can best be improved by providers listening to patients and carers and involving them in the planning, design and delivery of services. Integrating service-users' voices requires effective mechanisms to canvass opinion and implement change in practice. Too frequently, no such mechanisms exist in cancer care. A change in service culture, in which providers become encouraged to look at services from the point of view

of patients and carers and to involve them directly in planning and delivery, is nevertheless beginning to emerge.

2.35 The Department of Health and Macmillan Cancer Relief have launched a partnership project designed to support service-user involvement in cancer networks in England. The project aims to achieve this by:

- working with the 34 cancer networks in England to establish cancer partnership and user groups
- supporting the recruitment and training of user involvement facilitators
- monitoring the development of user involvement
- supporting user representatives to inform the development of cancer services and research at network and national levels
- linking effectively with other Department of Health initiatives and organisations (including the Patient and Public Involvement Strategy, PCTs and Cancer Services Collaboratives).

2.36 Among a range of features focusing on increasing user involvement, the project offers a 'tool-kit' on how to set up a user or partnership group, a directory of user and partnership groups in England and Wales, and training for group members and facilitators.

#### **G. Where now?**

2.37 The evidence of the survey work described above clearly suggests that services need to provide:

- better organisation, co-ordination and integration across cancer networks
- improved assessment of the individual needs of people with cancer, which includes all the domains of physical, psychological, social and spiritual care
- improved training for all health and social care staff in providing supportive and palliative care
- enhanced provision of supportive and palliative care services to meet needs which are currently unmet and to reduce inequalities in service provision and access
- active promotion of self-help and support groups, recognising the large management role people with cancer have in their own care and acknowledging the support they seek and receive from non-professional sources.

2.38 The NHS Cancer Plan (3) and the Cameron Report (10) make clear commitments to improving the experience of care of *all* people in England and Wales affected by cancer. This Guidance on service configuration is designed to help meet that aim.

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## 3. Co-ordination of care

### A. Introduction

3.1 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, in hospitals, in hospices and in care homes. This means that services need to work together effectively to ensure that patients' and carers' needs are assessed and addressed at all times.

3.2 Patients' and carers' usual professional carers should be at the core of these services, and should be able to:

- assess the care and support needs (including palliative care) of each patient and carer across 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 (1).

3.3 *A Policy Framework for Commissioning Cancer Services* (the Calman-Hine Report) (2) emphasised the need for care to be seamless from the patient's perspective. Continuity, or the experience of a co-ordinated and smooth progression of care from the patient's point of view, is a challenge to achieve. A number of elements need to operate effectively to create continuity, including:

- excellent information transfer following the patient
- effective communication between professionals and services, and with patients and carers
- flexible responses to individuals' changing needs over time
- care delivered by as few professionals as possible, consistent with need.

3.4 The Commission for Health Improvement/Audit Commission report (3), however, identified numerous deficiencies in the co-ordination of care for people with cancer. Unnecessary duplication of services has been found, leading to confusion between service providers and the waste of scarce resources. Communication between sectors (such as secondary and primary care) on patients' conditions, treatments and needs for supportive and palliative care is commonly poor. Patients may consequently suffer through delays in the provision of services.

3.5 Inadequate assessment of patients' physical symptoms and psychosocial needs lead to failure to recognise their needs for supportive and palliative care, resulting in necessary services being denied to them. Effective assessment hinges on the provision of appropriate education and training and the availability of skilled personnel to provide it.

3.6 Improved quality of life and higher patient and carer satisfaction with services will result if provision is better planned and organised at strategic and operational levels. Essentially, well co-ordinated services aim to address four key problems, each of which can lead to failure in service provision:

- patients' needs being unrecognised, and consequently not being met
- patients' needs being recognised, but relevant services not being available because, for example, the cancer network hasn't planned for them
- patients' needs being recognised, but health and social care professionals not accessing other relevant services because they are unaware of them
- patients' needs being recognised, the service being available and the patient being referred, but as a consequence of poor communication and lack of co-ordination between providers, services failing to bring maximum benefit to patients and carers.

3.7 All of these problems have to be addressed before a responsive and co-ordinated supportive and palliative care service can be delivered. At national level, many of these issues are being addressed through the establishment of a Supportive and Palliative Care Co-ordinating Group in England and the Cancer Services Co-ordinating Group in Wales.

3.8 The NHS Cancer Plan (4) stated that supportive care networks would be established alongside cancer networks. Since then, many local areas have developed a variety of groups tailored to meet local needs and work closely with cancer networks. Regardless of the organisational structure at local level, cancer networks, provider organisations, multi-professional teams and individual practitioners have an important role to play in ensuring that care is of the highest possible quality and is seamlessly co-ordinated from the perspective of patients and carers. This chapter sets out recommendations on how this can best be achieved.

## **B. Objectives**

3.9 The objectives are to ensure that:

- services required by patients are available to all who need them, when they need them
- patients who may benefit from services are identified and afforded access
- care delivered by an optimum number of providers in different locations is seamless yet non-overlapping from the perspective of patients and carers
- services are of the highest possible quality and are sensitive to people's needs and preferences.

## **C. Recommendations**

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

3.10 Each SHA/health board should establish a structure and process to plan and review local supportive and palliative care services. This should include all the relevant stakeholders in the provision and commissioning of such services, and should be done in conjunction with the cancer network. It will involve:

- assessing local need
- assessing current service provision
- making recommendations on service configuration and priorities for development to the Cancer Network Board and contributing to the service delivery plan
- overseeing the development of network-wide policies, guidelines and directories
- co-ordinating with Workforce Development Confederations in England on training needs
- developing joint operational policies and care pathways in partnership with local authorities and the voluntary and statutory sectors
- putting in place network-wide arrangements to ensure access by health and social care professionals to up-to-date clinical information about patients and carers
- ensuring the views of patients and carers are taken into account.

3.11 Each service provider organisation should nominate an individual to lead the development of supportive and palliative care services within the organisation and to contribute to the development of the network-wide strategy.

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

3.12 Assessment of patients' individual needs is a critical first step in ensuring that they receive the supportive and palliative care services they require. The assessment process should fully recognise that this is a shared function between patients and professionals. Patients should not be subjected to repeated assessments from different professionals aiming to elicit similar information. To facilitate this, teams/providers might consider using a unified assessment tool or developing mechanisms to share assessment data.

3.13 Assessments should encompass all the domains of supportive and palliative care. These include patients' and carers' needs and preferences in relation to:

- face-to-face communication and involvement in decision making
- written and other forms of information
- control of physical symptoms
- psychological support
- social support
- spiritual support
- rehabilitation
- complementary therapies
- carer support, self-management and peer support
- bereavement support.

3.14 Assessments should be undertaken by health and social care professionals who have received training in assessing patients' and carers' supportive and palliative care needs. The format for recording the findings from the assessment should be agreed locally, with findings being discussed at multi-professional team meetings.



3.15 While assessment should be an ongoing, continuous process throughout the course of a patient's illness experience, structured assessments should, as a minimum, be undertaken at each of the following key points:

- the time of diagnosis
- the commencement of treatment
- the completion of the primary treatment plan
- disease recurrence
- the point of recognition of incurability
- end-of-life care
- at any other time the patient requests it.

3.16 Following each assessment, potential interventions to manage problems and concerns should be discussed with patients and carers and a mutually agreed action plan formulated.

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

3.17 Prompt referral to services that may be of benefit should be discussed and agreed with patients following assessment. Teams should develop guidelines on referral.

3.18 A service directory should be 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 and by voluntary organisations, and professionally led and self-help groups. The directory should include information on accessing information services (see Chapter 5), psychological support services (see Chapter 6) and specialist palliative care services (see Chapter 7) *[other cross-references to come when Part B completed]*.

3.19 Patients and carers should be given information on who they can contact at any time of the day or night for advice, support and provision of services. Written information given to patients should include details of who they can contact locally if they have particular questions about their treatment and care, plus details of other confidential sources of information and support. Service providers may wish to consider the provision of a single, common 24-hour telephone access-point for patients and carers.

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

3.20 To enhance co-ordination within teams in relation to supportive and palliative care, teams should:

- discuss individual patients' needs at multi-professional meetings
- record the outcomes of these discussions and communicate them to the patient and carer (with the patient's permission) .

3.21 Teams should also develop their own policies/protocols in relation to communication, information and other key aspects of supportive and palliative care. This

might be facilitated by mapping the supportive care pathway for individual patients to identify which members of the team are providing specific aspects of supportive care.

3.22 All 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 in the Macmillan Cancer Relief/NHS Modernisation Agency Gold Standards Framework Project, in which general practices are asked to maintain a cancer register to record, plan and monitor patient care (5).

3.23 Teams should develop mechanisms to promote clinical continuity for patients. An individual, such as a community nurse, allied health professional or nurse specialist, should be nominated (in consultation with patients and carers) to take the lead on co-ordination within the team with respect to individual patients. A number of clinicians may perform this function on behalf of individual patients over time.

3.24 Each team should identify an individual to act in the capacity of administrative contact for patients and professionals. The role might involve organising multi-professional meetings, maintaining the mechanisms necessary to ensure teams are able to identify patients under their care, and acting as a common access point during normal working hours. Patients and teams/individuals involved in care provision should be informed about these individuals and made aware of how to contact them.

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

3.25 Patients move frequently between sectors (home, hospital and hospice, for instance), between teams (such as primary care, cancer and palliative care teams) and between health, social care and voluntary agencies. Co-ordination among these teams and services should be proactive to enhance continuity of care.

3.26 Co-ordination can be achieved in a variety of ways and will depend on local circumstances. Each team, however, should identify the other teams/services with which it most frequently interacts within and across different sectors, and should develop plans to promote co-ordinated care. These plans might include:

- undertaking joint clinics
- undertaking joint ward rounds
- participating in multi-professional meetings that include people from different sectors
- tele-conferencing.

3.27 Mechanisms to achieve comprehensive and timely information transfer between teams/services about patient care and treatment plans should be in place. This can be achieved in a number of different ways, and might involve electronic transfer of information, hand-over forms, or patient-held records and correspondence.

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

3.28 Wherever possible, care should be evidence-based and delivered in accordance with guidelines, policies and care pathways agreed at network level.

3.29 Relevant experts from different provider organisations should contribute to the development of policies related to the individual domains of supportive care. These policies should be reviewed regularly.

3.30 Network-wide audits, based on agreed policies, should be undertaken and results used to inform service development.

3.31 Research into supportive and palliative care should be encouraged and facilitated. The establishment of the National Cancer Research Institute and the Cancer Research Networks in England should facilitate the development and conduct of high quality clinical studies.

3.32 Progress should be reviewed with patient and carer representatives, and their views should be taken into account in the planning and operation of services. Network-wide arrangements for regularly and systematically obtaining patient and carer views about the experience of using supportive and palliative care services should be developed.

#### **D. Evidence**

3.33 There is no evidence to support the establishment of a particular structure and process to plan and review services in this area, and it is unlikely that any will be forthcoming. Needs assessment, however, has become an established method of determining and more closely meeting needs, and data on needs assessment are available in palliative care (6). There is significant risk of gaps and duplication in service provision if no systems are in place to link and co-ordinate the activities of providers of supportive and palliative care (3) [C].

##### **D.1 Assessment**

3.34 While the perceptions of patients, carers and health and social care professionals differ frequently, the process of assessment can produce a common understanding of needs and preferences. Studies have reported that the assessment of physical symptoms and psychosocial needs is often inadequate [B]. Patients' needs and preferences 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 (7).

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

3.35 The need for effective communication, co-ordination and continuity of care grows with the involvement of increasing numbers and categories of clinicians and interventions. Observational work has described patients' and carers' perspectives of continuity and barriers, and how this negatively influences the experience of care [B] (8).

3.36 Few studies examine the impact of continuity of care, or lack of it, on the process and outcomes of care (9). 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. This generated large increases in contacts and patient satisfaction [A].

3.37 Co-ordination of existing services through the introduction of organisational interventions such as community based nurse co-ordinators results in a small degree of benefit [A]. Guidelines to maintain interactions between services and the establishment of multi-professional care plans have been shown to be worthwhile [A], as have patient records designed to transfer information as patients move between home, hospital and primary care, seeing a diverse range of health and social care professionals in the process [A]. These innovations have been evaluated only within the context of palliative care, but it is likely that enhanced co-ordination and co-operation would result if similar interventions were also applied at other phases of the patient pathway. These now 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 Chapter 7, *Specialist Palliative Care*).

3.38 Further examples of tools to improve communication and co-ordination within and between teams include multi-professional meetings, case conferences, unified assessment tools, and patient-held records and hand-over forms. The value of many of these tools remains unsubstantiated, but some are currently being evaluated within the context of the Cancer Services Collaborative projects. One randomised trial found that professionals and patients value such initiatives [A].

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## 4. Face-to-face communication

### A. Introduction

4.1 Interpersonal communication is the process of information exchange among patients, carers and health and social care professionals. It is underpinned and enhanced by mutual understanding, respect and awareness of individuals' roles and functions, and is the process through which patients and carers are helped to explore issues and arrive at decisions.

4.2 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'* (1) is highly valued by patients and carers. It is the preferred mode of information-giving at critical points in the patient pathway, supplemented by written or multi-media materials and telephone communications, and in tandem with opportunities for reflection and questioning. There is a close relationship between giving and receiving information and the provision of emotional support.

4.3 Good communication is a prerequisite for enabling patients and carers to make informed decisions about care. Good communication among health and social care professionals, patients and carers, in which patients are encouraged to participate and to direct the flow of the communication, is likely to result in improved patient outcomes in terms of greater understanding, heightened ability to participate in the decision-making process, enhanced health-related quality of life and a better experience of care. Professionals should ask patients what they want to know, and not make assumptions about the level of information they require.

4.4 Good communication skills are therefore key to the delivery of effective supportive and palliative care services, but patients and carers frequently report health and social care professionals' communication skills to be poor.

4.5 Professionals may feel inadequately trained in aspects of communication such as listening, communicating significant news, explaining complex treatment options, exploring uncertainty (particularly in relation to prognosis) and discussing end-of-life issues. They may lack the necessary skills to be able to communicate effectively with the children and grandchildren of people with cancer, people with hearing, sight or combined sensory disabilities, those with learning disabilities, people who do not speak or understand English and those from minority ethnic backgrounds and traditions. And they may also lack skills in eliciting patients' needs for information and their desire for involvement in decision making.

## **B. Objectives**

4.6 The objectives are to ensure that:

- all patients and carers have the opportunity throughout the patient pathway to raise and discuss problems or concerns related to the disease, its treatment and its impact with professionals who are knowledgeable in the relevant aspect of care and who are skilled communicators
- all health and social care professionals listen to patients and carers, enabling decisions to be made in an atmosphere of genuine partnership
- all patients who have a desire to participate in decision making about their treatment and care are given the opportunity to do so.

## **C. Recommendations**

### **C.1 Overview**

4.7 Patients' and carers' preferences in relation to face-to-face communication and involvement in decision making should be assessed on an ongoing basis throughout the patient pathway.

4.8 All health and social care professionals must be able to judge whether they have addressed an individual patient or carer's communication needs; having recognised the need to access a more experienced professional, this should be arranged without delay. Patients may also make requests to see a more experienced professional, and may have strong opinions about whether or not individual professionals can address their communication needs.

4.9 Communicating significant news should normally be undertaken by a senior clinician (such as a consultant, specialist registrar, clinical nurse specialist or GP) who has received training and is an effective communicator.

4.10 The outcome of consultations with all health and social care professionals in which key information is imparted and discussed should be recorded in the patient's notes, and the patient should be offered a permanent record of important points relating to the consultation. The outcome of the consultation should be communicated to other health and social care professionals involved in the patient's care.

4.11 Patients should be offered the opportunity to discuss matters further with a professional of their choice.

4.12 For those individuals who cannot understand or speak English, or where patients have made a specific request, professional healthcare interpreters should always be present at consultations where key information is communicated and discussed and important choices have to be made.

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

4.13 All health and social care professionals should have the skills to communicate effectively with patients and carers, and should be alert to their possible needs and preferences in relation to face-to-face communication. Those who communicate particularly complex or distressing information should have enhanced skills.

4.14 All health and social care professionals should be able to judge whether they have sufficient knowledge and skills to communicate effectively with individual patients and carers, or whether a more experienced member of staff should be consulted.

4.15 Patients and carers should have access to professionals who have a level of communication skills appropriate to their current needs, and 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.

4.16 Face-to-face communication with patients and carers at key points of the patient pathway should, wherever possible, involve a senior clinician who has expertise in the disease and in the options for treatment and care, and who has received advanced communication skills training. If the initial communication of significant news has to be made by a clinician who has not had advanced training, the patient and carers should be offered an opportunity to discuss issues as soon as possible with a senior clinician with the requisite level of training.

4.17 A diagnosis should be communicated honestly to the patient with the minimum of delay. This information should be communicated in a comfortable, quiet area with privacy, ideally in the company of a close relative (if the patient so wishes) and in the presence of a specialist nurse where possible.

4.18 Patients' and carers' involvement in decision making should be facilitated where this is desired. People are likely to vary in the extent to which they want to participate in decision making, and also in which decisions they wish to be involved in. Preferences are likely to vary over time, and should be ascertained at key points in the patient pathway. Choices on involvement should be recorded and shared with all those involved in the care of the patient and carers.

4.19 Patients should be offered recordings or summaries of consultations in which key information is imparted and discussed. These could take the form of written summaries or, for people who have expressed a preference, audiotapes of consultations. The individual's choice on whether to accept this permanent record of the consultation, and whether he or she wishes to meet the professional at a later date to discuss the outcomes of the consultation, should be respected.

4.20 Provider organisations should ensure that suitably skilled interpreters (such as a professional healthcare interpretation service) or advocates, supported by cancer clinicians, are available for patients who cannot understand or speak English and who want or need them.

4.21 The potential role of family members as interpreters is acknowledged and, where the patient wishes and authorises it and the family member is willing, should be utilised. Services should not over-rely on family members as interpreters, however, and should only seek their participation in extraordinary circumstances or when the patient and/or family member specifically requests it.

4.22 It is not recommended that children be asked to provide interpreting services for parents or other members of their family, although there may be rare occasions when this is the most reasonable course of action.

4.23 Staff should be aware of the cultural aspects of face-to-face communication with patients and carers. They should respect individuals' cultural values and traditions when engaging in face-to-face communication.

4.24 Provider organisations should ensure suitable services are available for people with hearing, sight or combined sensory disabilities and for people with learning disabilities, to ensure they can participate fully in the process of information exchange.

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

4.25 It is essential that staff have the necessary communication skills to underpin and develop quality services. Effective communication is, to a large extent, dependent upon staff being trained in communication skills. Commissioners and Workforce Development Confederations in England should ensure that accredited training courses in communication skills are available for all health and social care professionals who come into contact with patients and carers.

4.26 Cancer networks, in association with Workforce Development Confederations in England, should decide which staff groups should be given highest priority for advanced training. For example, they may want to provide, as a first priority, advanced skills training courses 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.

4.27 Mechanisms should be developed to identify individual staff who may benefit from communication skills training, and a system should be established to evaluate how effectively they are communicating (for instance, through a performance appraisal process, which should involve a means of gathering the views of patients and carers). A process should be in place to effectively manage those members of staff who repeatedly demonstrate poor communication skills.

4.28 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.



## **D. Evidence**

### **D.1 Communication skills training**

4.29 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 study area, only one systematic review has been published on communication, and a systematic review has been recently submitted to the Cochrane Collaboration Effective Practice and Organisation of Care (EPOC) Group.

4.30 Training in communication skills can change healthcare 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.

4.31 Intensive communications skills training programmes have been demonstrated to improve senior doctors' communication behaviours [A]. Other studies support the positive effects of education courses in improving healthcare professionals' communication skills, with ongoing training being necessary to maintain skills [A].

4.32 Evaluated training programmes have varied in both 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 specific 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.

4.33 Improvements are most likely to be maintained where courses involve a large component of experiential learning over an extended period of time [B]. Most experience has been gained using a single profession approach to introducing training, but the benefits of training healthcare professionals together are increasingly acknowledged [A].

### **D.2 Communication process**

4.34 There is considerable evidence of problems with communication between healthcare professionals and patients and carers. A variety of methods aimed at improving the face-to-face communication process and supporting patient involvement in decision making (where they have expressed a preference for this) 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]. These can help patients by improving their recall and giving them the opportunity to consider information after the 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.
- Individualised patient and carer education sessions, usually provided by nurses [A].
- Supporting patient involvement in treatment decision-making through the use of decision aids [A]. While a recent systematic review (2) acknowledges that evidence about likely effects in people with cancer is limited, decision aids might 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], which has been found to be beneficial for patient participation in decision making and as preparation for significant consultations.

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

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## 5. Information

### A. Introduction

5.1 Patients and carers want and need high quality information, in a variety of formats, at all stages in the patient pathway. Many factors, including cultural and ethnic influences, play a significant part in determining how much information individuals will want, and the levels of information sought may be variable. The level and type of information individuals require is, however, entirely their prerogative, and health and social care professionals should be prepared to respond appropriately to the lead patients and carers give them. They also have a responsibility to ensure that needs and preferences for information are assessed on an ongoing basis.

5.2 The public may want information about risk factors for cancer, possible preventive measures, screening opportunities and symptoms that might indicate the presence of cancer. Most patients prefer to be given as much information about their illness as possible (both good and bad), including information about their condition, treatment options, likely benefits and adverse effects at the time of diagnosis, and some will wish information about their prognosis. Many want information about the services available to them at the time of referral to hospital and thereafter, including local and national information, support services and self-help groups who can provide practical advice and emotional support. After treatment, patients will want advice on resuming normal activities and details of who to contact if they are concerned. People with advanced cancer are likely to want information on the services available to them to enable them to live and die in the place of their choice.

5.3 Patients and carers cannot express preferences about their care and make choices on whether to be involved in decision making unless they are given sufficient and appropriate information. Many report, however, that they receive insufficient information from health and social care professionals, and that much of the information they receive is inadequate and of variable quality.

5.4 Problems are related to each of the three crucial elements of written information sharing:

- production (the process of producing written information)
- dissemination (distribution)
- access and availability (provision).

5.5 Many different organisations at local and national level are involved in the production of information, which can lead to unnecessary duplication of effort, inconsistency in quality and failure to use evidence-based methods. Information products may not be available where they are needed most - whether in a primary health care centre, a cancer unit or centre or the community – or may be out-of-date. 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. There is an enormous

amount of information on the World Wide Web (Internet), which can be of a variable quality. Many patients and carers currently lack the skills and resources to first access and then use this particular resource.

5.6 Health and social care professionals may under-estimate patients' desire for information, with the result that they do not always receive as much information as they wish. Patients should be encouraged to express their preferences and health and social care professionals should be wary of making their own assessment of what information patients are ready to receive.

5.7 Providing information to people with cancer and carers is an ongoing process, not a one-off activity. While it is important that the right products should be available at the time they are required, people also need to know that their information needs will continue to be met at each stage of the patient pathway.

## **B. Objectives**

5.8 The objectives are to ensure that:

- all patients and carers have access to high quality information materials where they need them and when they need them, in a format and at a level of complexity appropriate for them
- patients and carers are provided with assistance to help them understand information materials, should they so request
- patients and carers have access to sources of emotional support to help them cope with the impact of the information they have received.

## **C. Recommendations**

### **C.1 Overview**

5.9 People with cancer are entitled to receive all the information they wish to receive. Many will actively seek information from health and social care professionals, while others may be more reticent. In addition to responding to requests for information, health and social care professionals should assess on an ongoing basis the information needs and preferences of individual patients and their carers, asking what they would like to know and responding with appropriate information and materials.

5.10 Patients and carers should be offered a locally agreed selection of high quality information products relating to the disease, treatment options and available services, with access to further information should they require it.

5.11 Patients and carers should be offered assistance to help them understand the content of information products and should be advised of a contact should they wish further information.

5.12 People with cancer and carers should be offered support to help them cope with the emotional impact of the information they receive.

5.13 The adequacy of local provision of information for patients and carers should be reviewed regularly, in collaboration with groups of service users.

5.14 Decisions on local policy should be driven by the experiences of patients and carers identified from, for example, patient surveys.

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

5.15 There are a number of steps that need to be taken to ensure that high quality information is available and accessible to people with cancer and their carers as and when they need it. For this to happen, the information has to be:

- produced
- disseminated to a location where patients and carers can access it
- made available and accessible.

5.16 In England, the Coalition for Cancer Information should oversee the commissioning, design, quality assurance and compilation of a comprehensive range of high quality information products for people affected by cancer, covering three different levels of information (Box 5.1). The Coalition should accredit organisations that produce information at national and local level, according to specified criteria. In Wales, the Cancer Services Co-ordinating Group Communications Working Group aims to ensure that people with cancer and carers have access to appropriate information to aid their decision making and promote healthy living and self care.

### **Box 5.1 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.

5.17 Nationally produced and accredited information materials should be disseminated to all locations where people with cancer and carers can access them. Where possible, this information should be disseminated electronically to ensure ready access to up-to-date information. Where this is not possible, the material should be delivered in hard-copy format to key locations such as GP surgeries, primary health care centres, cancer centres, cancer units and hospices.

5.18 Policies should be developed at local (network/provider organisation) level, detailing which information materials should routinely be offered as a minimum at various stages in the patient pathway for patients with particular cancers. Additional information materials will be needed to meet individuals' requests and needs. A

representative of each multi-professional team should be involved in developing these policies. 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 and be supplemented with generic information that helps them put their own experiences in context.

5.19 Provider organisations (cancer centres, cancer units, hospices and primary care trusts) should ensure that patients and carers have easy access to a range of different information materials (books, leaflets, audio and videocassettes, internet, CD-ROM and DVD) that are appropriate for their age, culture, background and stage of disease. Within acute hospitals, this might be achieved by providing a dedicated cancer information centre, or through a facility that encompasses information for a broader range of diseases.

5.20 People with cancer are entitled to receive all the information they wish about their condition, care and treatment options. While many will actively seek information, others may be less inclined. Health and social care professionals must be prepared not only to respond positively to requests for information, but also to assess the information needs and preferences of individual patients and carers on an ongoing basis. The assessment process should identify how people with cancer and carers might wish information to be personalised or tailored.

5.21 Patients and carers should have the opportunity to talk through the information they have been given with a health or social care professional in a supportive and private environment.

5.22 Patients and carers should be offered advice, support and training on how to access and use information materials, including those located on the World Wide Web (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.

5.23 Provider organisations should ensure that arrangements are in place to translate information materials (where translations are not currently available) into a language the patient can understand. Organisations should purchase materials from an accredited information provider, unless materials in the appropriate language are not available.

5.24 Provider organisations should make arrangements to ensure the provision of suitable information resources for people with hearing, sight or combined sensory disabilities and people with learning disabilities. There should also be information sources suitable for sharing with children.

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

5.25 Cancer networks and Trusts providing cancer services should nominate a lead for cancer information. The network lead should oversee the development and implementation of effective strategies across all tumour types and locations. The Trust-level lead will ensure coherence across tumour types. He or she will be responsible for

ensuring that up-to-date materials are available and that patients actually receive them, and will also facilitate access to the World Wide Web (Internet) for patients. This may be a full-time post in larger acute Trusts.

5.26 Each specialist site-specific cancer team and each service (such as radiotherapy, chemotherapy, palliative care and primary care) within a Trust should nominate an individual to take a lead on information to implement policy at local level. The person may come from one of several professional backgrounds - a nurse specialist or community nurse, radiographer or pharmacist, for example – and will contribute to the development of network-wide policies for his or her area.

#### **D. Evidence**

5.27 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.

5.28 A systematic review has evaluated methods of giving information to patients with cancer and their carers [A], with strong evidence from studies that patients and carers value and benefit from receiving accurate and relevant information. Outcomes of giving 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.

5.29 Support for information being provided in a variety of formats and at all stages of the patient pathway is available, 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] (1).

5.30 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].

5.31 Features recognised as being key to the effective delivery of information include:

- patients being encouraged to express their own preferences, and health professionals being wary of making decisions about what information patients are ready to receive

- the provision of verbal information, reinforced with written sources; additional information could be provided by means of video or audiotape instead of in writing, where appropriate
- assistance to understand information
- provision of opportunities for further questions and reinforcement
- health and social care professionals being prepared to repeat relevant information as often as the patient needs, or wants, to hear it.

5.32 The evidence further emphasises the importance of tailoring information to match patients' and carers' educational background, cultural orientation, and general level of comprehension (2). Patients also prefer information based on their own medical records, rather than general information [A]. The best way to achieve this is not currently known, but many Cancer Collaborative projects aimed at improving the experience of care are piloting different ways in which to tailor written information [C]. Personal Information Files have been implemented in some clinical areas (3) [B], and recordings or summaries of consultations have also been provided (see Chapter 4, *Face-to-Face Communication*).

5.33 If the information needs of patients and carers are to be met, it is acknowledged that health and social care professionals are likely to need support (2). 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 (4) [C]. Instruments are available to assess the quality of written information and also to assist in the production of good quality information materials (5-7).

5.34 Promoting access to information is a prime concern, and there are many locations where cancer information could be made available to patients and carers. 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 [B] (8,9), but the number of people contacting and using them suggests a need for more sources of information.

5.35 The most effective ways of extending access to cancer information for those from black and ethnic minority communities are currently being explored through the National Opportunities Fund *Living With Cancer* projects, and an evaluation has just got underway at City University, London.

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## 6. Psychological support services

### A. Introduction

6.1 Psychological distress is an understandable response to a traumatic experience for people affected by cancer. Many people who feel distress seek help informally from friends, relatives or peers, or from professionals who provide psychological support (see Chapter 00, *Social Support*).

6.2 A degree of psychological distress is to be anticipated in patients with cancer. About 15% of patients experience mild to moderate degrees of psychological distress at any one time in the first year following diagnosis, and between 10-15% of those with advanced disease will have levels of psychological morbidity severe enough to warrant a specific psychological therapy.

6.3 Acknowledging that for many people the level of distress they are experiencing is normal and understandable does not, however, imply that it is either negligible or unmanageable; people in psychological distress can benefit from psychological support.

6.4 Many people will assess their own degree of distress and seek help from those who are closest to them, but this does not obviate the need for professionally initiated assessment. As patients and carers experience different levels of severity and different types of psychological distress, it is important that they are assessed individually. Health and social care professionals should be able to distinguish between normal reactions to cancer and pathological responses, and refer people to services accordingly.

6.5 Health and social care services offer a range of psychological interventions for people with cancer. The selection of an appropriate psychological intervention will depend on the nature and severity of the person's psychological problem, his or her previous psychological problems, availability of social support and prognosis.

6.6 Psychological support services can be accessed from non-professional sources (such as self-help and support groups) and the statutory sector (primary care teams, mental health services and social services, for example) in community, secondary and tertiary care settings. Non-professional sources of support, such as self help, family, friends and support groups, offer assistance that is often different from, but of equal value to, professional support.

6.7 The Commission for Health Improvement/Audit Commission report (1), however, showed that patients' psychological symptoms are commonly not being identified, and that patients and carers are not getting sufficient access to psychological support services. Health and social care professionals often lack assessment skills in this domain of care and may underestimate the effectiveness of psychological support. Some don't know to whom they can turn for advice and support for patients and carers in distress.

6.8 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 professional disciplines can and should provide. Professionals offering different levels and types of psychological intervention lack co-ordination; consequently, psychological support services are neither available to, nor accessed by, many people living with cancer who have psychological care needs.

## **B. Objectives**

6.9 The objectives are to ensure that:

- the psychological needs of all patients and carers are assessed on a continuous basis throughout the patient pathway, with particular attention being given to points that are recognised as being particularly challenging, such as the time prior to diagnosis and after bereavement
- patients and carers are offered a level of support appropriate to their needs, and that those found to be experiencing psychological problems are referred to professionals with the relevant level of specialist expertise
- the psychological needs of staff who are caring for patients and carers facing difficult circumstances are adequately met.

## **C. Recommendations**

### **C.1 Overview**

6.10 The psychological wellbeing of patients and carers should be explicitly assessed at key points in the patient pathway.

6.11 Patients and carers should be supported to pursue their own solutions to problems, but those who are found to have significant levels of distress or psychological morbidity should be referred without delay to services in which staff are trained to provide specialist psychological care.

6.12 If a patient is unfit to travel, the psychological support service should be delivered wherever he or she is located.

6.13 Emergency psychological care should be made available when necessary.

6.14 Psychological assessments and interventions should be undertaken in facilities that are quiet and which confer privacy.

6.15 Staff providing psychological care should be adequately trained, and mechanisms to ensure support should be available.

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

6.16 Commissioners and cancer networks should work to ensure that all patients have access to an appropriate level of psychological support. A network-wide psychological

support service, consisting of professional and non-professional workers who are competent in a variety of psychosocial interventions, would facilitate this aim. The service's objective would be to optimise the psychological adjustment of people living with cancer through systematic and routine assessment, ensuring that those with psychological needs are provided with appropriate support. Patients, carers and relatives may experience different levels and types of psychological distress, and the function of the service would be to provide a comprehensive range of interventions aimed at matching psychological support to the individual needs of people affected by cancer.

6.17 In addition to providing direct psychological support, the service network should contribute to the provision of education, training and continuing professional development (CPD) in psychological care for health and social care professionals.

6.18 It is recommended that a five-level model of psychological assessment and support be developed and implemented in each cancer network (Table 6.1). Patients and carers have significant personal resources on which they can draw. Utilising inner personal resources and seeking support from family and friends, self help and self-help and support groups enable people with cancer to seek personal solutions to their own concerns (see Level 0 of the five-level model of psychological support). Beyond this level, much of the basic psychological support is likely to be provided by doctors, nurses, radiographers and other health and social care professionals who are directly responsible for the care of people with cancer (see Levels 1 and 2). More severe psychological distress will be managed by a variety of psychological specialists, including counsellors, clinical psychologists, psychotherapists and liaison psychiatrists (see Levels 3 and 4). It may be necessary for psychological specialists to work across different components of the cancer network - primary care, cancer units, cancer centres, hospices and the community.

<b>Level</b>	<b>Group</b>	<b>Assessments</b>	<b>Interventions</b>
<b>0</b>	Patients and carers	Recognition of their own needs for help and support	Self-management and harnessing sources of support (such as self help, self-help and support groups)
<b>1</b>	All health and social care professionals	Recognition of psychological needs	Effective information-giving, compassionate communication and general psychological support
<b>2</b>	Health and social care professionals with additional expertise	Screening for psychological distress	Psychological interventions (such as anxiety management and problem solving)

<b>3</b>	Trained and accredited professionals	Assessed for psychological distress and diagnosis of some psychopathology	Counselling and specific psychological therapies, such as cognitive behavioural therapy (CBT) and solution-focused therapy, delivered according to an explicit theoretical framework
<b>4</b>	Mental health specialists - clinical psychologists and psychiatrists	Diagnosis of psychopathology	Specialist psychological and psychiatric interventions

6.19 The function of each different level of care provision is as follows:

**Level 0** encompasses patients' and carers' assessments of their own status. It involves recognition of their psychological coping resources and sources of help and support. Patients might choose to seek personal support from family, friends, peers, self-help and support groups, and may develop a significant repertoire of self-management strategies.

**Level 1** involves all staff directly responsible for patient care and is focused on general emotional care. Staff should be able to:

- communicate honestly and compassionately with those affected by cancer
- recognise psychological needs
- treat patients and carers with kindness, dignity and respect
- establish and maintain supportive relationships.

**Level 2** involves psychological interventions delivered by trained and supervised health and social care professionals to manage acute situational crises encountered at key points in the patient pathway. Appropriate interventions include anxiety management training and problem solving. Among others, clinical nurse specialists could potentially be trained and supported to deliver such interventions as an integral part of their practice. Professionals operating at this level should also be able to screen for psychological distress.

**Level 3** involves specific psychological therapy, such as counselling delivered according to an explicit theoretical framework by a trained, accredited and supervised counsellor, to manage mild to moderate levels of psychological distress, including anxiety, depression and anger. Specific psychological therapies at this level are also appropriate for dealing with mild to moderate cancer-related concerns such as worries about treatment, relationships with hospital staff and financial matters, as well as the more spiritual issues that having a life-threatening condition raises.

**Level 4** involves specialist psychological and psychiatric interventions delivered by trained and supervised mental health specialists to manage moderate to severe mental health problems experienced by those affected by cancer. These include severe

depression and anxiety, organic brain syndromes, severe inter-personal difficulties, alcohol and drug-related problems and personality disorder.

6.20 The model recognises the range of psychological skills and expertise that patients may draw on and represents the diversity of psychological skills possessed by various disciplines. While it is expressed as an hierarchy, no individual level is more important than another.

6.21 It may not always be possible to make a clear distinction between the boundaries of expertise of various professionals (particularly in the case of Level 2 and Level 3). Some individuals will have developed a special interest and expertise and will have received additional training in one or more aspects of psychological therapy (not confined to, but including, social workers, occupational therapists and palliative care nurse specialists), and there is likely to be some overlap between the levels.

6.22 The professionals involved in offering different levels and types of psychological interventions should develop and implement mechanisms to co-ordinate their service provision to ensure that patients and carers are offered the intervention most appropriate to their needs. This should involve the use of referral guidelines for each level/type of psychological intervention, including counselling, clinical psychology and psychiatry.

6.23 If different psychological specialists within the psychological support service work in an effectively integrated way, referrals for psychological intervention could initially be made to the overall service; a system of triage could then be used to define the particular level/type(s) of intervention offered to individuals with cancer. This approach would be based on an acceptance that choice of treatment should be guided by the informed preference of the patient, and that the therapeutic approaches can be effectively used to treat a variety of mental health problems.

6.24 The assessment of patients' needs and resources for coping should be carried out on a continuous basis throughout the patient pathway. Health and social care professionals responsible for the patient's cancer care should elicit concerns, worries and feelings by establishing trust and listening in a permissive and non-judgemental manner. The assessment process itself may lead to the resolution of concerns and should result in appropriate psychological support being made available. Patients experiencing significant psychological distress should be referred for specialist psychological support/intervention.

6.25 All health and social care professionals should be able to recognise psychological distress and should be competent in avoiding causing psychological harm to patients and carers. They should be able to identify when they have reached the boundary of their competence and should be referring the patient to a more specialist service. All patients with cancer should be systematically screened for possible psychological problems at key points in the patient pathway. Designated professionals (such as nurse specialists, social workers or GPs) who have been appropriately trained in screening for psychological distress should undertake these assessments.

6.26 Emergency psychological support services should be available for patients who are in severe distress. Healthcare professionals should have 24-hour access to advice from a mental health team on caring for patients who have acute psychological problems.

6.27 Appropriate facilities should be made available for undertaking psychological assessments and interventions. Facilities should reflect the needs of patients and carers for privacy and comfort.

6.28 Most patients requiring a specific psychological therapy or specialist psychological/psychiatric intervention will be able to travel to a specialist facility. If a patient is unfit to travel, the service should be made available wherever he or she is located (at home, on a hospital ward, in a hospice or in a care home), with appropriate safeguards in place to protect privacy.

6.29 Psychological care services should have agreed processes for transfer of information within their service and with referring services/practitioners and other teams involved in the care of individual patients and carers. Information should include the findings from individual patient assessments, proposed treatment plans and outcomes of treatment. There may need to be an agreed formal process within teams for managing sensitive and private issues.

6.30 Service directories related to supportive and palliative care should include information on psychological support services and the range of support groups available locally, in hospital and the community.

6.31 In collaboration with local provider-led and voluntary support groups, cancer networks should develop locally agreed guidelines that are consistent with the Declaration of Good Practice for Cancer Self-help and Support Groups produced by Cancerlink (see also Chapter 00, *Social Support Services*, and Chapter 00, *Carer and Bereavement Support Services*).

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

6.32 Practitioners who will be responsible for the delivery of psychological care at each of the different levels should be identified.

6.33 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. Psychological care experts with extensive experience in cancer and who have worked with oncologists and palliative care specialists might be the most appropriate providers of training.

6.34 An individual (or individuals) should be identified within each cancer site-specific team to take responsibility for providing Level 2 care (that is, screening for psychological distress and providing simple psychological interventions).

6.35 Those working at Levels 3 and 4 should normally provide CPD opportunities, training and clinical supervision for individuals working at Level 2, and must also have their own CPD, clinical supervision and ongoing support needs met. Psychological specialists will also play a significant role in the development and maintenance of communication skills through teaching and training (see Chapter 4, *Face-to-face Communication*).

6.36 All staff need ongoing training and support if good psychological care is to be provided. Working with those who deliver psychological support services (at Levels 2, 3 and 4), providers should ensure that ongoing support is available for all staff delivering psychological care in proportion to their role in psychological service delivery. A variety of different methods might be used to achieve this, such as clinical supervision, significant event analysis and staff support groups.

## **D. Evidence**

### **D.1 Overall benefit**

6.37 While there is no formal evidence on the potential benefits of implementing this particular model of psychological assessment and intervention, a considerable body of evidence supports the effectiveness of different elements of the model. Four systematic reviews found benefits 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 adherence to cancer treatments.

6.38 The model also has the potential to:

- reduce the likelihood of litigation
- reduce the risk of occupational stress.

6.39 However, a more recent appraisal, which included the studies in these reviews and others, questioned the consistent conclusions reached in previous reviews about the benefits of psychological therapies for patients with cancer. They suggest that a more cautious approach towards such therapies should be adopted.

6.40 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 interventions from a trained cancer health professional or a specific psychological therapy. Ten per cent experience moderate to severe levels of psychological distress at any one time and are likely to benefit from either a specific therapy or 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.

6.41 Establishing a comprehensive and co-ordinated psychological support service will provide major benefit to all those affected by cancer.

## **D.2 Assessment**

6.42 There is fairly strong evidence that healthcare professionals' current abilities to detect the psychological needs of people with cancer are limited. Abilities can be developed through the provision of training designed to improve assessment skills, and which focuses on the structure and coverage of individual assessments [B].

## **D.3 Benefit of different approaches**

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

6.44 Interventions have been delivered 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.

6.45 While the magnitude of benefit to be derived from effective communication and psychological interventions by trained cancer health and social care professionals is difficult to quantify, counselling and specialist psychological and psychiatric interventions are likely 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].

6.46 There is strong evidence from meta-analyses to suggest that specialist psychological and psychiatric interventions (Level 4) confer benefit in terms of reducing anxiety and depression and bringing about emotional and functional adjustment. It is beyond the scope of this review to consider psychopharmacological interventions, but services should ensure they follow the most effective practice.

6.47 Specific psychological therapies, such as counselling and cognitive behavioural therapy (Level 3), 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].

6.48 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, promote anxiety management, improve ability to adjust to life situations and problem solve [A]. Psychoeducational 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 certain symptoms, such as pain, nausea and breathlessness [A].

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

6.49 Psychological support serves to enhance the ability of health and social care staff and volunteers 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].

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## 7. Specialist palliative care services

### A. Introduction

7.1 A significant proportion of people with advanced cancer suffer from a range of complex problems – physical, psychological, social and spiritual – which cannot always be dealt with effectively by generalist services in hospitals or the community. Much less frequently, people with early (curable) cancer may experience a similar range of problems and may benefit from specialist input. Their families and informal carers may also need expert support during their lives and in bereavement (see Chapter 00, *Carer and Bereavement Support Services*).

7.2 In response to these needs, hospices and specialist palliative care services have been established across the country over the past three decades. These services are provided by the voluntary and statutory sectors and cover the spectrum of community, hospice, day therapy and hospital settings. In most parts of the country, however, they have evolved in a fragmentary way.

7.3 Access to and availability of specialist palliative care services is variable and inequitable throughout the country. The survey undertaken by the NCHSPCS on behalf of the Department of Health (1) 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.

7.4 The need for specialist palliative care services is related to the number of people dying from cancer per unit of population, and is highest in areas with greater socio-economic deprivation. Detailed analysis of the NCHSPCS survey shows that those geographical areas with the greatest need tend to have fewer palliative care resources than those with lowest need. Older people and those from black and ethnic minority groups do not appear to access services in the proportions that would be expected.

7.5 Around 50 % of patients with cancer die in acute hospitals. However, the appraisal of hospital services in England against the National Cancer Standards, which was undertaken in 2001, showed that only 55% had a full multi-professional palliative care team including consultants and nurse specialists. Less than half of the 176 hospital palliative care teams appraised were able to provide 24-hour access to advice.

7.6 Concerns have been expressed that the needs of people with cancer in care homes are not being adequately met. Community palliative care services vary considerably in their staffing levels and therefore in their ability to provide advice and/or direct patient support at weekends and outside normal working hours.

7.7 Concerns have also been expressed that patients' needs are not always adequately assessed and that the potential benefits of referral to specialist palliative care services are sometimes not recognised soon enough. This can cause unnecessary suffering to patients.

7.8 In addition to their role in the delivery of care, specialist palliative care services have an important function in providing education and training on the principles and practice of palliative care to the wide range of generalists who offer care to people with advanced, progressive, life-threatening disease and their carers (see Chapter 8, *General Palliative Care Services*). They also have a role in research and audit.

## **B. Objectives**

7.9 The objectives are to ensure that:

- those patients who may benefit from specialist palliative care services are identified and referred without delay
- all patients who need specialist palliative care services can access services as and when they need them, both from hospitals and from the community.

## **C. Recommendations**

### **C.1 Overview**

7.10 All patients with advanced cancer should have their physical, psychological, social and spiritual needs assessed by a competent health care professional (see Chapter 8, *General Palliative Care Services*).

7.11 Specialist palliative care teams should work closely with general providers to ensure that appropriate patients access specialist services at the right point in the patient pathway.

7.12 All specialist palliative care service providers should have agreed mechanisms for co-ordinating care with their referring services/practitioners and have agreed eligibility criteria for referral.

7.13 A range of specialist palliative care services for which there is evidence of benefit should be available across the country. The level of service provision should be appropriate to the needs of the local population (taking account of cancer death rates, deprivation levels and other key factors).

7.14 These services are likely to include, as a minimum:

- multi-professional specialist palliative care teams providing assessment, advice and care for patients in all locations
- specialist inpatient facilities (such as hospice beds) for patients with complex problems which cannot be adequately managed in other settings
- bereavement support services (see Chapter 00, *Carer and Bereavement Support Services*).

7.15 Each specialist palliative care service should have an appropriate range of staff to provide the expertise needed by patients.

7.16 Each service should have sufficient staff to enable it to deliver care seven-days-a-week with appropriate out-of-hours cover, and to contribute as needed to the education and training of general staff.

7.17 Within a cancer network, all specialist palliative care service providers should develop and implement guidelines against which practice in relation to the assessment, treatment and care of patients can be audited and monitored.

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

### **Organisation and planning of services**

7.18 Cancer networks should ensure they provide an appropriate range and volume of specialist palliative care services to meet the needs of the local population. The assessment of needs should take account of numbers of deaths from cancer and the levels of deprivation in the population served, together with any other important local factors.

7.19 The range of services provided should include:

- multi-professional teams providing assessment, advice and care for patients in acute hospitals, community hospitals, at home, in care homes and in other institutions which provide care for people with cancer
- specialist inpatient facilities for patients with complex problems which cannot be dealt with adequately in other settings
- specialist day therapy facilities. *[This is a provisional recommendation and is subject to alteration following work on Part B. It will be particularly influenced by the topics on social support, rehabilitation and complementary therapies]*

7.20 Mechanisms should be developed and 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:

- all patients with advanced cancer should have their needs for palliative care assessed by a competent healthcare professional (see Chapter 8, *General Palliative Care Services*); the findings of this assessment should be shared with the specialist palliative care team, if appropriate
- service directories related to 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 Chapter 3, *Co-ordination of Care*)
- cancer network-wide referral guidelines and eligibility criteria should be developed and disseminated
- specialist palliative care teams in hospitals, hospices and the community should work in close partnership with teams who refer patients to them; collaborative working might include participation in joint clinics (for example, with oncologists), multi-professional meetings and joint ward rounds
- teams should ensure that points of contact are clearly defined and widely known.

7.21 All specialist palliative care service providers within a network should develop common approaches to 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 multi-professional palliative care teams (hospital and community)**

7.22 Each multi-professional team should be able to provide specialist advice, support and care for patients and carers. The service should be provided in conjunction with the GP and primary health care team and specialties within the hospital, as relevant. The level of intervention will vary according to assessed needs of the patient and carer, and will range from a purely advisory role to taking a lead in providing care. The team should also be in a position to provide advice and support to, and education and training for, professional colleagues.

7.23 To provide this level of service, a specialist palliative care team is likely to require, as a minimum, the following core members:

- palliative medicine consultants
- palliative care nurse specialists
- social workers, counsellors or other staff able to provide psychological and social support and advice on benefits for patients and carers
- team secretary/administrator.

7.24 In addition, each palliative care team needs access to a range of other specialist expertise. This will ideally be provided by relevant staff as full members of the team, and includes:

- the full range of psychological support services (see Chapter 6, *Psychological Support Services*)
- physiotherapy
- occupational therapy
- dietetics
- speech and language therapy
- spiritual support (often provided by a chaplain)
- pharmacy
- oncology and radiotherapy.

7.25 Each multi-professional team should work to agreed network guidelines/protocols. The care of individual patients should be reviewed at multi-professional team meetings held at least weekly. Records of attendance at meetings 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.

7.26 The team should be staffed to a level sufficient to undertake direct assessment of people with cancer (at home or in hospital) during normal working hours, seven-days-a-week. In addition, there should be access to telephone advice at all times (24-hours-a-

day). This is considered a minimum level of service. It is desirable that provision be made for bed-side consultations in exceptional cases outside normal working hours.

7.27 The team should have access to office space to enable the safe storage and efficient retrieval of records and information materials, and effective communication within and between teams.

### **Inpatient specialist palliative care services**

7.28 Commissioners should ensure that 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.

7.29 Cancer networks should establish guidelines which set out admission criteria for patients who warrant admission to specialist palliative care inpatient facilities.

7.30 Inpatient specialist palliative care facilities should be able to provide care for patients with distressing symptoms and other complex needs which are not readily relieved in the home or other care settings. To provide this level of service, inpatient specialist palliative care units are likely to be served by the following core staff, as a minimum:

- palliative medicine consultants, supported by experienced medical staff to provide 24-hour cover
- palliative care nurse specialists
- nursing staff who have completed an introductory programme in palliative care
- social workers, counsellors or other staff able to provide psychological and social support and advice on benefits for patients and carers
- administrative support.

7.31 In addition, each inpatient facility needs access to a range of other specialist expertise. This includes:

- the full range of psychological support services (see Chapter 6, *Psychological Support Services*)
- physiotherapy
- occupational therapy
- dietetics
- speech and language therapy
- spiritual support (often provided by a chaplain)
- pharmacy
- oncology and radiotherapy.

7.32 It is recognised that this full range of expertise may not be available within each inpatient facility. Where this is the case, it will be necessary to establish formal arrangements between providers of neighbouring services to ensure access. Staff in these cases will be likely to be members of several services simultaneously.

7.33 Inpatient specialist palliative care facilities should adhere to specifications set out in the Care Standards Act (2000). While the Act does not specifically relate to the NHS, statutory providers should strive to ensure that their facilities match the standards described within the Act.

### **Specialist day therapy facilities**

**[THIS SECTION IS PROVISIONAL – WILL BE AMENDED WHEN WORK ON RELEVANT TOPICS IN PART B IS COMPLETE...]**

7.34 Existing specialist day therapy facilities are variable, with some adopting a social support or respite model of care, and others adopting a clinical or symptom control model. The skills and expertise available within day therapy facilities are therefore also variable, and are intrinsically linked to the remit and function of the facility. Specialist day therapy facilities should nevertheless be able to provide a range of palliative interventions in a context of social interaction, mutual support and friendship. Such interventions might be delivered during the course of a day attendance or by appointment at a more formally arranged clinic.

7.35 To provide this level of service, a specialist palliative care day therapy facility is likely to require, as a minimum, the following core members:

- palliative medicine consultants
- palliative care nurse specialists
- social workers, counsellors or other staff able to provide psychological and social support and advice on welfare benefits
- administrative support.

7.36 In addition, each day therapy facility needs access to a range of other specialist expertise. This includes:

- physiotherapy
- occupational therapy
- pharmacy
- psychological support services (see Chapter 6, *Psychological Support Services*)
- dietetics
- speech and language therapy
- spiritual support (often provided by a chaplain)
- complementary therapies
- creative activities
- oncology and radiotherapy.

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

7.37 Cancer networks should assess their needs for each of the professional groups contributing to specialist palliative care teams (as core or extended members) and for hospice staff. In England, workforce development should be planned in collaboration with Workforce Development Confederations.



7.38 The role of specialist palliative care teams (based in hospices, hospitals and the community) in delivering education and training to general staff should not be underestimated. A 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 network-wide education and training programmes.

## **D. Evidence**

### **D.1 Multiprofessional teams**

7.39 Studies and systematic reviews have demonstrated quantitative and qualitative benefit from adopting a multi-professional approach with specialist input [A]. This leads to a higher quality service than conventional care being offered alone.

7.40 Reviews also provide support for specialist palliative care teams working in different locations, such as homes, hospitals and in-patient units or hospices, as a means to improve outcomes for patients with cancer. Teams have a positive effect on patient outcomes, independent of team (or service) make-up or study design. Similar or improved outcomes for patient satisfaction, pain and symptom control and family anxiety when compared with conventional care for hospices and home care have been demonstrated. There is currently no evidence on the efficacy of specialist palliative care day therapy as there are few comparative studies. *[The evidence review team is aware that at least two UK-based comparative studies are about to report. Therefore day care will be re-reviewed in Part B, so that these studies can be included and their social and spiritual effects can be more fully considered.]*

7.41 There is great variation in the ‘type’ of intervention reported, and specific activities of teams are often not clearly defined. There is no strong evidence to support a particular team composition in each of the various settings, and no research evidence on the level of specialisation required for team members. Better outcomes tend to be observed, however, where the teams are categorised as ‘specialist’ and consist of multi-professional trained staff, compared to those which have a nurse only and/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.

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

7.42 Patients with cancer who have moderate to highly complex palliative care needs can receive high quality care in a variety of settings, providing there is adequate input from specialist palliative care services.

7.43 The need for effective communication, co-ordination and continuity of care becomes more prominent with the involvement of increasing numbers and categories of clinicians.

7.44 Given the complex nature of service provision, it is essential that mechanisms for co-ordination and communication are in place to ensure appropriate and timely access to

specialist palliative care services. The multi-professional palliative care team approach is one means by which continuity of care can be achieved. Few studies have specifically examined continuity of care *per se*, but some have looked at aspects of care that are thought to improve as a result of achieving continuity.

7.45 The importance of effective communication and co-ordination between in-patient and home care teams has been demonstrated in terms of reducing number of days spent in hospital and the number of home visits; nurse co-ordinators appear to be particularly advantageous for this function [A].

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

**Reference**

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## 8. General palliative care services

### A. Introduction

8.1 People with advanced cancer spend most of the last year of life in the community, with approximately 25% of people with cancer dying at home and a further 25% equally divided between hospice and nursing homes.

8.2 Palliative care may frequently be provided by the health and social care professionals who usually provide services to patients in the community or in hospitals, with or without additional support from specialist palliative care services. Nurses and doctors are predominately responsible for providing the core elements of care, supported by other disciplines in health and social care services. The contribution relatives and friends make in supporting people with cancer physically and emotionally is significant, and providing support for carers is integral to good palliative care (see Chapter 00, *Carer and Bereavement Support*).

8.3 Primary care teams, particularly GPs and community nurses, provide frontline care. Primary palliative care, particularly care of terminally ill people, is an essential and intrinsic part of quality care delivered by the primary health care team. The majority of GPs still regard the care of patients with palliative care needs as an inherent and important part of their role. However, while they might have up to 40 patients with cancer at any one time under their care, palliative care comprises a small part of an average GPs workload, with 5-6 patients dying from cancer per GP per year (one or two of which will take place in the home). It is only one of many pressing issues making demands on GPs' time, skill and expertise, and has to be balanced with other priority needs and areas of care.

8.4 Community nurses might carry a somewhat larger caseload of patients with advanced incurable illnesses than GPs, but although many are experienced practitioners, they may have received little post-registration palliative care training. Education initiatives for community nurses on the principles and practice of palliative care, funded by the Department of Health working in partnership with Macmillan Cancer Relief and other key stakeholders, are currently addressing training needs in England. Nursing homes and community hospitals, where a considerable number of patients are cared for towards the end of life, are run by generalist staff who have variable levels of experience and knowledge in palliative care.

8.5 In secondary care, people with advanced cancer who require inpatient care in hospitals are managed in a variety of different wards - medical, surgical, gynaecological, or care of the elderly, for instance – as well as on oncology wards. Although up to 50% of people with cancer die in an acute hospital, the staff on these wards may have little specific expertise in the management of the problems faced by patients with advanced cancer, or in dealing with end-of-life issues.

8.6 The availability and involvement of specialist palliative care colleagues in multi-professional teams is inconsistent across the country which, when allied to a lack of recognition by generalists of when to seek specialist help, may serve to deny patients access to expert opinion and management at crucial points in the patient pathway.

8.7 Primary and secondary care services may be neither sufficiently resourced nor sufficiently responsive to provide adequate round-the-clock palliative care (NHS Direct is being proposed as the first main contact for all out-of-hours care by 2004). Out-of-hours medical care in the community is frequently provided by large co-operatives or deputising agencies, and on-duty doctors may not have ready access to the information they need to provide appropriate advice and care. The new GP contract will have an impact on the provision of out-of-hours services.

8.8 There is inadequate access to key services such as 24-hour nursing care and pharmacy services, and necessary equipment may be lacking. Access to controlled drugs out of hours is a considerable problem currently; it may be a significant barrier to good symptom control and a contributing feature of many emergency admissions. The Department of Health has commissioned the National Prescribing Centre (NPC) to develop a good practice guide for practitioners and health bodies about the management of controlled drugs in primary care.

8.9 The needs of patients receiving palliative care services are subject to change over very short periods of time. Needs also change out of hours, when support services may be sparse. With general palliative care services often struggling to meet needs within office hours (or 'in hours'), it is inevitable that needs occurring out of hours will place enormous strains on support services. Improvements in 'in hours' community services will therefore reduce the burden on out-of-hours provision and the need for crisis secondary or specialist care.

8.10 Lack of key services may consequently lead to patients being admitted to hospital a few hours before death, where they might be cared for by professionals who are inexperienced in recognising the signs of impending death and reluctant to discuss end-of-life issues. Inappropriate medical interventions, failure to recognise rites associated with particular cultural traditions and faith groups, and the provision of insufficient information to relatives on what actions to take following the death compound what is likely to be an already distressing event for carers and staff.

8.11 Improvements in general palliative care education, organisation and provision, better availability of round-the-clock services in the community, and closer working between generalists and palliative care specialists will enable more patients to die well in the place of their choosing.

## **B. Objectives**

8.12 The objectives are to ensure that:

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

## **C. Recommendations**

### **C.1 Overview**

8.13 All patients with advanced cancer should have their physical, psychological, social and spiritual needs, and their preferences for care, assessed on a regular basis.

8.14 Patients' usual health and social care professionals should know when to seek advice from, or refer to, specialist palliative care services.

8.15 Ongoing care of patients with advanced cancer provided by usual professional carers in hospital and the community should be based on locally agreed protocols and guidelines.

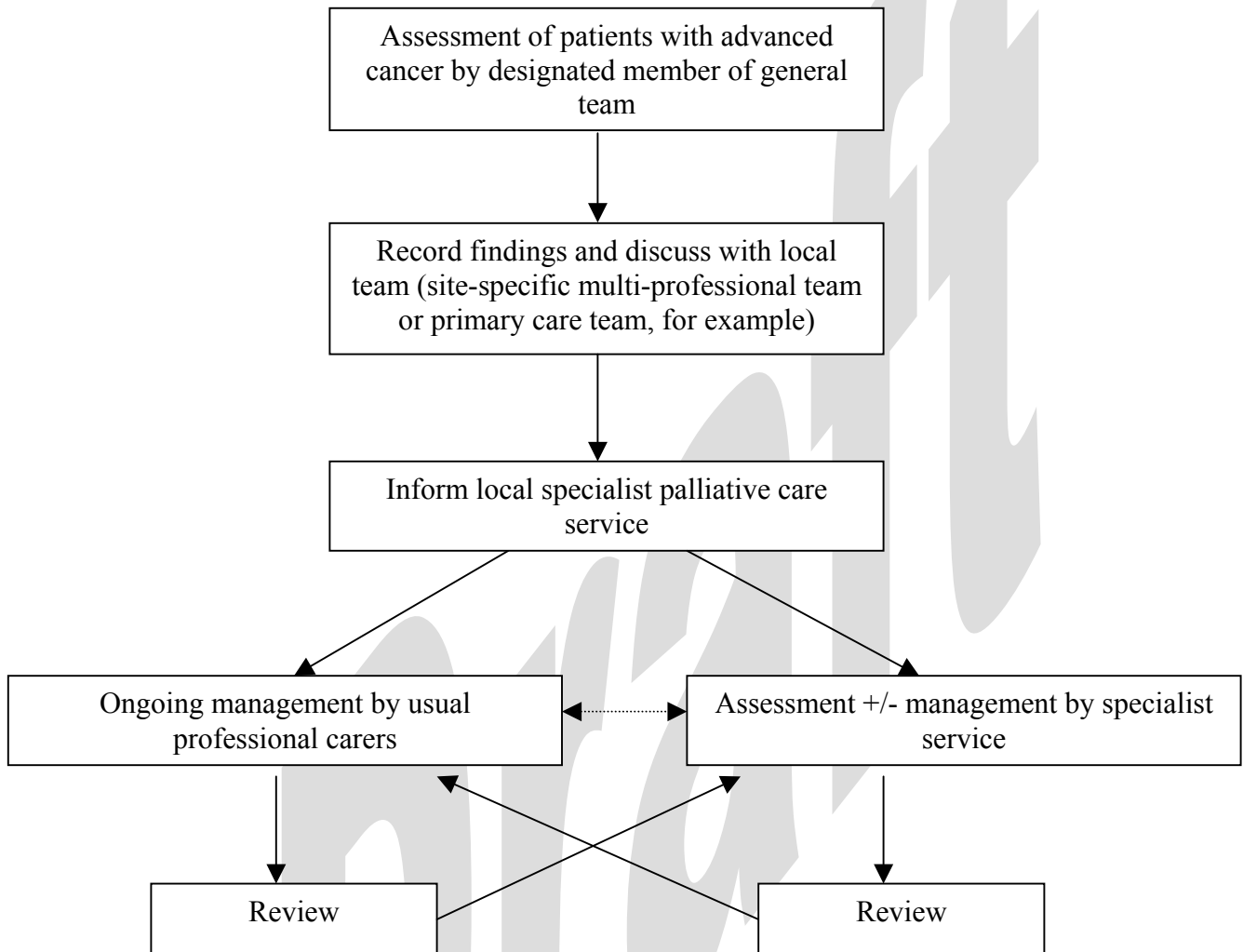
8.16 Staff providing general palliative care should be trained in the assessment of the palliative care needs of patients and carers and in the basic principles and practice of palliative care.

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

8.17 Each patient with advanced cancer should have his or her palliative care needs systematically assessed across the domains of physical, psychological, social and spiritual needs, on a regular basis. As needs at this stage of the patient pathway can change rapidly, the need for re-assessment should be revisited at frequent intervals.

8.18 The assessments should be made by a healthcare professional who has received post-registration education and training in palliative care ( Figure 8.1). This might, for example, be a GP, a hospital doctor, a district nurse, a cancer site-specific nurse specialist or a nurse on a hospital ward that deals with considerable numbers of patients with cancer. If the patient is being cared for in a location where no healthcare professional has received such education and training (some hospital wards and care homes, for instance), the local specialist palliative care team should be asked to undertake the assessment and offer advice and management

**Figure 8.1 Proposed pathway for management within general setting**



8.19 The results of assessments should be recorded in the patient's records and should be formally discussed within the team providing care.

8.20 The local specialist palliative care service (community or hospital based, as appropriate) should be made aware of the patient's need for care and the findings of the assessment. A joint decision can then be made on whether further involvement by the specialist palliative care team is required at this point in the patient pathway.

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

8.22 Network-wide protocols and guidelines should be developed and implemented in relation to symptom control, palliative interventions for common emergencies (such as spinal cord compression and superior vena cava obstruction) and care of dying patients and their carers. These should be subject to regular audit.

### **Community-specific issues**

8.23 Medical and nursing services should be available 24-hours-a-day. Commissioners and providers should work together to develop policies for the provision of out-of-hours palliative care.

8.24 Where 24-hour district nursing services are not available, alternative means of providing patients with advanced cancer with access to trained nurses around the clock should be agreed between the PCT and the cancer network. To inform the development of these arrangements, the nature of care that might be required from a trained *nurse*, as opposed to a trained *carer*, should be agreed.

8.25 Mechanisms should be developed to ensure the transfer of relevant clinical information about patients between those providing care during normal working hours and those providing services and care out of hours.

8.26 As end of life approaches, provision should be made for continuous support to be provided in the patient's home, in compliance with the wishes of patients and their carers. This may involve either trained nurses or trained carers, according to the patient's needs.

8.27 Equipment needed to enable patients to continue living in the community should be available without delay, and should be removed promptly when no longer required.

8.28 Arrangements should be made to ensure access around the clock to drugs that may be required in the patient's home. Cancer networks should work towards existing recommendations that relate to the availability of drugs at the time and in the place of consultation (1).

### **Hospital-specific issues**

8.29 As part of the initial palliative care assessment of hospital inpatients, consideration should be given to the optimal location of care within the hospital. This could, for example, be a surgical ward, a coronary care unit, an elderly care ward or an oncology ward, depending on individual needs.

8.30 If the patient is to be cared for in a location in which there are no health professionals with post-registration experience/training in palliative care, the hospital specialist palliative care team should be asked to advise on management.

8.31 Lines of responsibility for out-of-hours medical care should be agreed and recorded in the patient's notes. The on-call team should be made aware of the patient's condition. Ways of accessing advice from cancer and/or specialist palliative care staff should also be documented in the patient's records.

8.32 The discharge of a patient from secondary care should only occur when all the necessary support services are in place, unless the patient insists on taking discharge before arrangements can be confirmed. Providers may consider the benefits of identifying a designated discharge co-ordinator to liaise with relevant services.

8.33 The patient and carers should be aware of the person or service to contact if problems arise following discharge.

8.34 Flexible systems to obtain rapid discharge should be in place to enable the safe transfer of patients who wish to die at home.

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

8.35 Building on the Department of Health-funded community nurse training programme in palliative care, networks should identify priorities for the further development of the general workforce. 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.

8.36 Education and training should be designed to enable health and social care professionals to conduct assessments of palliative care needs, deliver general palliative care services and recognise when to seek advice or refer to specialist services. Staff will require designated time to fulfil their education and training requirements.

8.37 Education and training programmes should include staff working in all care settings, including care homes, community hospitals and acute hospitals.

## **D. Evidence**

### **D.1 Assessment**

8.38 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. Better methods of assessment and the use of guidelines and protocols may improve this situation (2) [B][evaluation data being sought].

8.39 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) (3), communicating to relatives and within teams, monitoring patient progress, and stimulating referral to specialist palliative care services [B].

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

8.40 The involvement of specialist staff in the support and education of healthcare professionals, particularly nurses, has been shown to facilitate communication between



patients and their usual professional carers and to enhance symptom management [A]. Chapter 7, *Specialist Palliative Care Services*, gives further evidence on outcomes associated with involvement of specialist palliative care teams.

8.41 Generally, audit and observational data point to the fact that those managing patients with advanced cancer may not always follow guidelines and protocols (for example, in relation to 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 [A] (4).

8.42 Specifically, the introduction of clinician-developed guidelines on pain has been demonstrated to improve pain management, when introduced as part of a broader education programme [A]. Care pathways, such as the Liverpool Care Pathway for the Dying Patient (5), are designed to co-ordinate and standardise care across different settings and provide an instrument for developing, monitoring and improving the delivery of palliative care (6). In particular, the care pathway approach provides a tool through which general healthcare workers can be empowered to improve care.

8.43 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 [C] (7).

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

8.44 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 (8). It is also recognised that patients change their minds about preferences over location.

8.45 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, drugs and equipment being unavailable in the location and at the time required, and difficulties that result from GP services provided by co-operatives/deputising services (9-11).

8.46 The provision of 24-hour 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**

8.47 Survey data demonstrate that although many healthcare professionals are extremely competent and inspire high satisfaction levels among carers (12), some have inadequate knowledge and feel ill-prepared to care for patients in the palliative phase of their illness [B] (13,14).

8.48 The benefits of providing education and training to enhance the knowledge, skills and competence of healthcare 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 (15, 16).

8.49 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].

8.50 The Gold Standards Framework Programme for Community Palliative Care [C](17) aims to improve palliative care provided by the whole primary care team, and is designed to develop the practice-based organisation of care of dying patients within primary care. It focuses on improving continuity of care, teamwork, advanced planning (including out of hours), symptom control and patient, carer and staff support. A planned, step-wise approach to change is utilised, with centrally supported facilitated groups, a toolkit and practice-based external education sessions. The Gold Standards Framework is currently being implemented, and evaluative data are not yet available.

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Draft

# Appendix 1

## How the Guidance was produced

A1. 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 the process set out by NICE in *The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups* (1). The Figure (Fig. A1) depicts key stages in the development of the guidance.

A2. A wide range of individuals representing service users, professionals and policy-makers were involved in generating the Guidance, which has arisen from proposals for recommendations which were then critically appraised in the light of research evidence. The final guidance document was drawn from material generated as a result of a number of complementary activities. These included the proposal generating event, evidence review, guided discussion with commissioners and users and the deliberations of the Editorial Board (see Appendix 2 for membership).

### User involvement

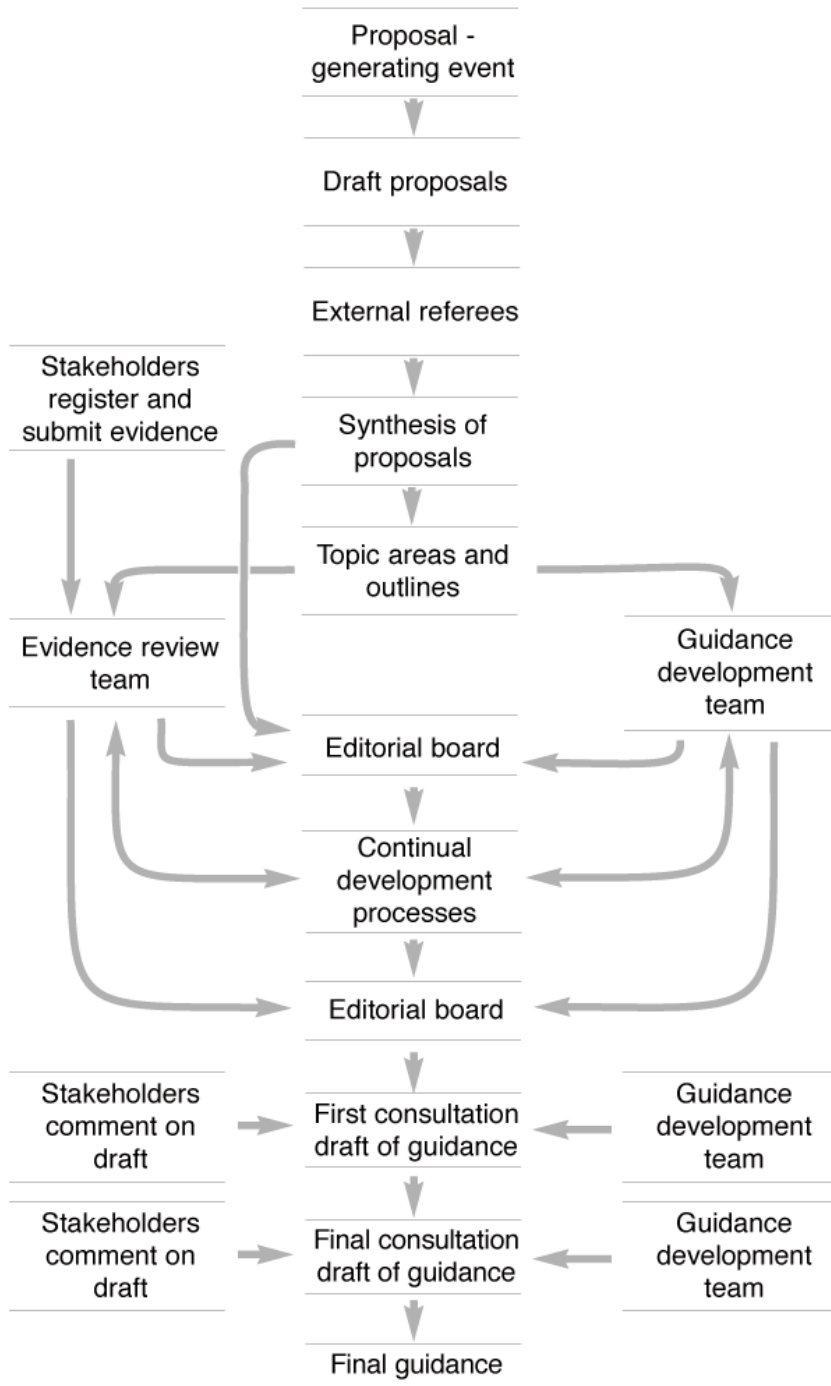
A3. The involvement of people with cancer and their carers has been central to the process. Among their contributions has been:

- 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 with two service-user members, including a representative from Cancerlink
- representation on a focus group of service users who met twice during the process and commented and contributed to successive drafts of the Guidance (see Appendix 3 for membership)
- significant involvement at the different consultation stages prior to the publication of the Guidance.

### Stages in the process

A4. 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, healthcare commissioners and academics from around the country (Appendix 4) 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.

# Overview of development of supportive and palliative care guidance



A5. The proposals were sent to referees representing a spectrum of clinical opinion, those likely to use the eventual guidance, and organisations and individuals representing the concerns of patients and carers (Appendix 5). The original proposals and referees' comments then went forward to the evidence review stage.

A6. The Editorial Board, who oversaw the production of the Guidance, reflected on the proposals and relevant comments from referees with the Guidance Development Team (Appendix 6) 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 focus groups, one of commissioners of services (Appendix 7) and the other of service users (Appendix 3).

A7. 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, a number of individuals were invited to comment by the Guidance Development Team (see Appendix 5).

### **The evidence review**

A8. Systematic reviews of the research literature were then carried out by the Evidence Review Team (Appendix 8) based at the Department of Palliative Care and Policy, King's College, London.

A9. 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*.

A10. The quality of individual research studies was graded following the criteria listed in Table A1. This is the same system used in the reviews undertaken by NHS Centre for Reviews and Dissemination at the University of York as part of the site specific *Improving Outcomes* series (2).

<b>Table A1 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>	

A11. The quality of combined research was also graded using the hierarchy of evidence employed in the *Improving Outcomes* manuals (2):

- 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.

A12. 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).

A13. 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 care 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.

A14. 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 (SchHARR) at the University of Sheffield [to be included at a later stage in guidance development].

### **Outcomes of the process**

A15. The process culminated in the production of two large sources of information: *The Guidance Manual*, which is based on all the available sources of information; and *The Research Evidence*, a condensed version of systematic reviews of research used to inform the guidance and published in electronic format [website address to come...]. The recommendations are also available in a version for the public.

A16. The production of the guidance was funded by the National Institute for Clinical Excellence (NICE).

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1. National Institute for Clinical Excellence. *The Guideline Development Process – Information for National Collaborating Centres and Guideline Development Groups* London: NICE. December 2001.

2. Mann T. *Clinical Guidelines: using clinical guidelines to improve patient care within the NHS*. London: Department of Health. 1996.

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## Appendix 2

### Members of the editorial board

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Ms Jane Bradburn Dr Ged Corcoran	Cancer Voices Consultant, Macmillan Cancer Relief Macmillan Consultant in Palliative Medicine, University Hospital, Aintree
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Dr Rob George	Consultant in Palliative Medicine, Camden and Islington Primary Care NHS Trust
Ms Maureen Hunter	Rehabilitation Services Manager, The Royal Marsden NHS Trust, London
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Mr Stewart Sinclair Rev. Peter Speck	Carer Trust Chaplaincy Team Leader, Southampton University Hospital NHS Trust <b>[awaiting new preferred title..]</b>
Dr Keri Thomas Dr Rob Thomas	Macmillan GP Advisor, West Midlands and Wales Consultant Oncologist, Addenbrooke's NHS Trust, Cambridge

## **Appendix 3**

### **Focus group: service user membership**

Sylvia Berry, Liverpool Cancer Support Centre  
Andy Caswell, Rushden, Northants  
Anna Craven, Skipton, North Yorkshire  
Anna Louise Dugdale, Rotherham Hospice, Rotherham, South Yorkshire  
Denise Fuller, Horsham, West Sussex  
Jeremy Gambrill, Cuckfield, West Sussex  
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Lindi Shaw, Rotherham, South Yorkshire  
Stewart Sinclair, London  
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The focus group was facilitated by Ms Jane Bradburn, Cancer Voices Consultant, Macmillan Cancer Relief

## Appendix 4

### Participants in the supportive and palliative care proposal-generating event

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Prof. Malcolm McIlmurray	Oncologist, Royal Lancaster Infirmary
Ms Judith McNeill	Chief Executive, Cancerlink
Ms Barbara Monroe	Director of Patient Services, St Christopher's Hospice, London
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Sir N Young  
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**The following individuals were invited by the Guidance Development Team to comment on the draft Guidance**

Full list to come...

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## Appendix 6

### Guidance development team

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Ms Jane Bradburn	Cancer Voices Consultant, Macmillan Cancer Relief
Ms Jo Luthert	Healthcare Consultant, London
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## Appendix 7

### Focus group: Commissioner membership

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Mrs Maureen Breen	Network Manager, North West Midlands Cancer Network
Ms Judith Brodie	Head of Cancer Support Services, CancerBACUP
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The focus groups were 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.

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## **Appendix 8**

### **Evidence review team**

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