HANDBOOK *of* PALLIATIVE CARE

THIRD EDITION

EDITED BY

CHRISTINA FAULL, SHARON de CAESTECKER, ALEX NICHOLSON & FRASER BLACK

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Handbook of Palliative Care

Yvonne Carter has been very much in our minds throughout the preparation of the third edition of the *Handbook of Palliative Care.* Sadly, she was not part of the team on this occasion. After many years living with cancer, she died in 2009 but her voice has been heard loudly by us, giving encouragement and direction throughout the process. We dedicate this edition to her.

Handbook of Palliative Care

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Foreword

Every minute over 100 people die in the world but far too many people still do not get the palliative and end-of-life care they need or want. Even patients in countries with well-developed health-care systems such as Europe, Australasia, and North America, who could benefit from the full range of palliative care support and services, never have that opportunity. The consequence is that many die with the distress of uncontrolled symptoms and with relatives and carers who are unsupportive. A difficult time may be made worse because no one has established the wishes of the patient, and they die in a place they would not have chosen and are perhaps subject to inappropriate and futile interventions, such as resuscitation, that they would have declined. Furthermore, it is still unfortunately true that access to palliative care services varies according to age, diagnosis, gender, and geography, and the basic levels of palliative care that are available are of inconsistent quality. The time has come to change this and to change it for good.

My vision is for a "good death" to be the norm. We only get one chance to get it right for people living in the late stages of incurable illness and those who are dying. I believe the *Handbook of Palliative Care* will undoubtedly contribute to achieving this vision by providing evidence-based knowledge for doctors and nurses, and for other members of the multiprofessional team. This new edition is highly impressive and should be required reading for all those involved in delivering palliative care at any level wherever they work in the world. As a practicing general practitioner, I know on a daily basis how a clinician can be faced with complex clinical and ethical dilemmas in patient management. I would find a resource like this book very reassuring, providing as it does a wide range of trusted knowledge, experience, and expertise.

An ageing population with complex health and social care needs requires a new caring approach and a new deal for the dying. All health-care systems need to effect a change in clinical practice to recognise the dying patient earlier and improve access for these patients to the palliative care and hospice approach—for example, through use of supportive and palliative care registers—particularly for patients with conditions other than cancer. The development of better generalists is a must, as is implementing comprehensive evidence-based guidelines for palliative care. Key to grasping this opportunity is development of the workforce.

And we need to achieve fundamental changes in public and professional attitudes. A society that is more comfortable with talking about death, dying, and bereavement is much needed. I am therefore delighted that the handbook includes a chapter on communication skills. I also welcome the new chapter on spirituality in this edition. Spirituality is often the missing piece in palliative care plans, even though meeting the individual spiritual needs of a patient is an important part of that person's journey at the end of life.

In 2008, readers of the British Medical Journal voted "palliative care beyond cancer" as the area of health care in which doctors could make the most improvement. This is an outstanding book that is to be thoroughly commended for its broad range of clinical issues and particularly for its focus on noncancer palliative care. All clinicians will recognise that the noncancer patient presents challenges when we are trying to determine the starting point for the last few months of life, but this is critical if we are to identify those patients who need palliative attention and for whom we should be starting advance care planning discussions. I am glad to see practical guidance on this area of practice.

We know that there is still considerable room for improvement in palliative care. Although maybe 70% of people would prefer to die at home, more than half currently die in hospital in the United Kingdom. This is replicated in many countries in the developed world. The realities of living and dying well are at the heart of palliative care, an important clinical area that deserves to be more widely understood.

I restate my ambition to reduce the fear of dying and make a "good death" the norm. The authors of this book share their expertise, experience, and wisdom in guiding us towards these goals. I am confident that good progress will be made and I invite readers of *The Handbook of Palliative Care* to join me in making good end-of-life care not only a priority but also a reality.

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Preface to the Third Edition

In preparing the third edition of the *Handbook of Palliative Care*, we are encouraged and grateful that the previous editions have been so well received. However, both the specialty of palliative care and the place it occupies in modern health and increasingly social care continues to evolve. The third edition seeks not only to retain the strengths of the previous editions but also to prove responsive to feedback and to have been adapted with additional content and chapters reflecting relevant developments in palliative care practice and scope.

Our main aim has been to provide a handbook that is informative and practical, thereby supporting the care professional delivering palliative care in any setting and enhancing the quality of both everyday and unusual clinical practice. Thus, the content on assessment and symptom management, communication skills, and ethics remains key and emphasises the essential nature of a holistic, patient-centred approach to care. We have also included sections that allow more expansion into some philosophical and historical background in order to provide breadth and balance in a handbook about a type of care that is wide-ranging and deeply rooted. For example, the chapters *User Voices, Palliative Primary Care*, and *Spirituality in Palliative Care* support this ambition. These dual approaches are intended to improve the understanding of what really “makes palliative care work” as well as increasing the confidence and skills of those working to support patients and their families. As in previous editions, emphasis is placed throughout on the importance of teamwork and highlighting the multidisciplinary nature of palliative care. Never forgetting that “the team” must include the patient and those who are important to them.

Taking a global perspective, the need for palliative care remains great. Estimates suggest that more than 100 million people worldwide would benefit from palliative care provision every year, yet only a small fraction of those individuals in need actually receive the necessary support. Worldwide we know that close to three-quarters of people diagnosed with cancer and other life-limiting illnesses present late with incurable disease and that this is accompanied by a burden of significant symptoms and suffering that is both physical and nonphysical.

There continues to be an expanding knowledge and recognition of how palliative care can benefit not only patients with cancer but also those with noncancer illnesses, and the updated chapters include significant new content in the areas of heart failure, renal failure, advanced respiratory diseases, and HIV and AIDS. We have also added a new chapter *Palliative Care for People with Advanced Dementia,* arguably the biggest issue on the horizon. The chapter *Palliative Care for Adolescents and Young Adults* now includes the important issue of transition from children’s to adult palliative care for the growing number of young people with life-limiting diseases surviving to their early adult years.

Advance care planning is another area that is recognised increasingly to be fundamental to sound holistic patient-centred palliative care provision, and a new chapter gives the reader a sure grounding in key considerations.

In this third edition, a decision was made to expand the remit of the text beyond the perspectives of the United Kingdom, and the result has been a book that has been authored and edited by a team drawn from the United Kingdom and North America. Contributing to this edition are new authors from two longstanding hospice palliative care programmes in Canada. Victoria Hospice was among the early hospice palliative care programmes established in Canada, and Canuck Place Children’s Hospice in Vancouver was the first free-standing children’s hospice in North America.

There is so much to learn from one another in making progress to address the need for increased access to palliative care worldwide, and we hope that this collaboration has added a richness and variety to the handbook’s content that will appeal to all readers. Naturally, there are some differences in terminology and language and we have tried to accommodate these as far as possible while leaving the content intelligible to all. We recognise that

Table P.1 Drug names used in Handbook of Palliative Care.

Recommended International Non-proprietary Name (rINN) (European market)	British Approved Name (now replaced by rINN)	United States Adopted Name (used in USA in preference to rINN)
Aspirin		Often known as aspirin but also **Acetyl salicylic acid**
	No UK equivalent	**Benzonatate**
Calcitonin	Salcatonin	**Calcitonin**
Chlorphenamine	**Chlorpheniramine**	**Chlorpheniramine**
Colestyramine	Cholestyramine	
	Not marketed in UK	**Desipramine**
Furosemide	Frusemide	**Furosemide**
Glitazones		**Thiozolidinediones**
Guaiphenesin		**Guaifenesin**
	Not marketed in UK	**Hydrocodone**
Hyoscine		Scopolamine
	No UK equivalent	**Levodropropizine**
Levomepromazine	**Methotrimeprazine**	
Levothyroxine	**Thyroxine**	
	No UK equivalent	**Miltefosine** (hexadecylphosphocholine)
Paracetamol		**Acetaminophen**
Pethidine		**Meperidine**
Phenobarbital	Phenobarbitone	
Rifampicin		Rifampin
Riluzole		
Risperidone		
S		
Senna		
Sertraline		
Silver sulphadiazine		
Sodium citrate		
Sodium cromoglicate	**Sodium cromoglycate**	Cromolyn sodium and Sodium cromoglycate

This table lists drugs which may be known by different names in Europe and North America. Names shown in **bold** appear in the text.

drug names vary in different countries—sometimes subtly, sometimes significantly—and have included a list of drugs used in the handbook to aid the reader to align their European and North American names (see Table P.1). For important drugs that are mentioned often in the text, both names are used. Spellings have followed the British tradition. Where terminology varies, we have tried to explain this within the text of the relevant chapter. An interpretation of abbreviations also appears in the front of the book (page xvi).

It is our hope that this third edition will succeed in its aims of keeping prominent those parts of hospice and palliative care that we know make a difference to patients and families while also incorporating new knowledge and approaches that will help improve the provision of palliative care to patients and families worldwide. Thank you for your efforts in this regard by using this handbook and by providing the care that you do to patients, families, and communities around the world.

Acknowledgements

This book has only been made possible by the hard work of many contributing colleagues and we hope that this edition does justice to the efforts of all the individuals who have given so much of their time over and above their normal duties and responsibilities. We are aware of how much personal complexity some of the writing team have been dealing with and we should like to pay tribute not only to their determination in fulfilling their commitment to this book but also to their efforts in trying to ensure that high-quality palliative care is available to those who need it. We would particularly like to acknowledge Richard Woof who contributed so much to the first edition and whose legacy lasts in this third edition.

Acknowledgement: Cover illustration

A water-colour titled *Between Night and Day* (1995) reproduced with kind permission of the artist Michele Angelo Petrone who sadly died in 2007. It is reproduced with kind permission of the MAP Foundation, an arts in health organization founded by Mr. Petrone to promote expression, communication, and understanding for people affected by life-threatening illness. Michele painted and wrote of his experience during treatment for Hodgkin's disease:

'As time goes by, night follows day and day follows night- a natural cycle without beginning, without end and without gaps. Life's cycle continues without interruption, or at least it should do. Suddenly illness arrives, uninvited, unexplained. I found myself caught between life and death, light and dark, banished to an unknown place- between night and day. The illness forced itself into my life where there was no place for it. The arrival of the illness stole a place and time that should have been destined for better things.'

List of Abbreviations

AIDS	acquired immune deficiency syndrome
ADL	Activities of Daily Living
ACP	advance care planning
ADRT	advance decision to refuse treatment
AD	advance directive
ADA	After Death Analysis
AND	allow natural death
ALS	amyotrophic lateral sclerosis
BPI	Brief Pain Inventory
CPR	cardiopulmonary resuscitation
CVD	cardiovascular disease
CP	care professional
CKD	chronic kidney disease
COPD	chronic obstructive pulmonary disease
CNSs	clinical nurse specialists
CHF	congestive heart failure
CDs	controlled drugs
DNACPR	do not attempt cardiopulmonary resuscitation
DNAR/PND	do not attempt resuscitation/permit natural death
EoLCS	end-of-life care strategy
ESRD	end-stage renal disease
EAPC	European association for palliative care
GI	gastrointestinal
GMC	General Medical Council
GP	general practitioner
GFR	glomerular filtration rate
GSF	Gold Standards Framework
HF	heart failure
HIV	human immunodeficiency virus
HD	Huntington's disease
IV	intravenous
LPA	lasting power of attorney
LANSS	Leeds assessment of neuropathic symptoms and signs
LLCs	life-limiting conditions
LCP	Liverpool Care Pathway
MSCC	malignant spinal cord compression
MLD	manual lymphatic drainage
MCA	Mental Capacity Act
MR	modified release
MND	motor neuron disease
MNDA	Motor Neurone Disease Association
MDT	multidisciplinary team
MS	multiple sclerosis
MSA	multiple system atrophy
MD	muscular dystrophies
NG	nasogastric
NHS	National Health Service
NICE	National Institute for Health and Clinical Excellence
NPSA	National Patient Safety Agency
NMDA	N-methyl-D-aspartate
NIPPV	noninvasive positive pressure ventilation
NIV	noninvasive ventilation
NSAID	nonsteroidal antiinflammatory drug
NR	normal release
OT	occupational therapy
PO	oral
PD	Parkinson's disease
PCT	primary care trust
PEG	percutaneous endoscopic gastrostomy
PPI	proton pump inhibitor
RFA	radiofrequency ablation
SSRI	selective serotonin reuptake inhibitor
SNRI	serotonin noradrenaline reuptake inhibitors
SLD	simple lymphatic drainage
SC	subcutaneous
SVC	superior vena cava
TENS	transcutaneous electrical nerve stimulation
TCA	tricyclic antidepressant
WHO	World Health Organization

1

The Context and Principles of Palliative Care

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Introduction

Palliative care touches almost every health and social care professional. Irrespective of their particular specialty, most professionals will encounter people with advanced illness, and the care of people in the last months and weeks of life is an important part of their work [1]. This can be an extremely rewarding area of practice, and professional satisfaction is enhanced by confidence in core skills and knowledge of basic physical and nonphysical symptom management [2,3].

Palliative care should not be seen as an alternative to other care. It is a complementary and vital part of total patient management that should be integrated, in people with advanced illness, alongside appropriate care to reverse illness or prolong life. The challenges of the parallel approaches of trying to improve physical well-being and prolong life while also addressing the realistic probability of deterioration and death are significant, especially in those illnesses characterised by episodes of acute deterioration. Perhaps one of the biggest challenges we face in medicine and indeed in society is balancing the clinical and ethical "pros and cons" (weighing the burdens, benefits, and risks) of investigation and intervention in those with advanced illness and in the frail elderly. In the United Kingdom, the General Medical Council (GMC) has recommended that death should be an explicit discussion point when patients are likely to die within 12 months [4,5]. Box 1.1 identifies the mandated expectations in this guidance [5].

Box 1.1 Mandated expectations of the GMC guidance—Treatment and care toward the end of life: good practice in decision making [4,5]

- Identification of patients approaching the end of life.
- Provision of information on this matter.
- Determination of preferences regarding life-sustaining treatment including cardiopulmonary resuscitation (CPR).
- Documentation of the above in an unambiguous and accessible format.
- Communication of decisions within relevant health-care teams.

The majority of care received by patients during the last year of life is delivered by general practitioners (GPs) and community teams. A systematic review of GP involvement in this care reported the following [3]:

- GPs value this work and it is appreciated by patients.
- Palliative care is sometimes delivered less well in the community than in other settings.
- Some GPs are unhappy with their competence in this field.
- With specialist support, GPs demonstrably provide effective care.
- The confidence of GPs and the understanding of the potential of team members increase through working with specialist teams.

Of course, many patients spend significant time in hospitals during their last year of life, and it has been estimated that 20% of hospital beds are occupied by patients near the end of life who often do not need, or want, to be there [6]. Despite the majority wishing to die at home, almost 60%

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of patients still die in a hospital in the United Kingdom [7]. The lack of recognition of the fact that patients are nearing the ends of their lives and open discussion of this with the patients and their families is the major barrier in achieving better outcomes including enabling people to die where they would most want to [6,8,9].

Palliative care is more than just end-of-life care. Some of the newest challenges are in providing effective support for those living with cancer, or other advanced illness, for long periods of time who are suffering from a complex mix of effects of the cancer or human immunodeficiency virus (HIV) or other condition. There is considerable unmet need in supporting people with the effects of the treatments for the disease and the psychosocial and psychospiritual impacts of facing not only the fear of recurrence and death but also the ongoing symptoms such as fatigue, disability, and change of role and social and family dynamics [10,11].

There is a broad range of challenges in delivering high-quality palliative, end-of-life, and terminal care including professional competence and confidence, teamwork and organisational factors, and access to resources. Patients with advanced disease can present some of the most challenging ethical, physical, psychological, and social issues, and it is vital to have a grasp of the communication skills required to explore these issues effectively. It is also important to be able to identify when referrals to specialists and other services are needed.

This chapter outlines the development of palliative care, defines the principles that underpin effective care, and presents an overview of the attainment and assessment of quality in palliative care.

What are hospice, palliative care, and end-of-life care?

Much of our understanding and knowledge of the philosophy, science, and art of palliative care has developed and grown through the work of the hospice movement. Dame Cicely Saunders worked with patients suffering from advanced cancer and undertook systematic narrative research to understand what patients were experiencing and needed. The bedrock of the hospice philosophy, in Western society at least, is that of patient-centred holistic care focusing on quality of life and extending support to significant family and carers:

> What links the many professionals and volunteers who work in hospice or palliative care is an awareness of the many needs of a person and his/her family and carers as they grapple with all the demands and challenges introduced by the inexorable progress of a disease that has outstripped the possibilities of cure [12].

Box 1.2 Etymology

The word “hospice” originates from the Latin *hospes* meaning host; *hospitalis*, a further derivative, means friendly, a welcome to the stranger. The word *hospitium* perhaps begins to convey the vital philosophy of the hospice movement: it means the warm feeling between host and guest. Hence, a hospice denotes a place where this feeling is experienced, a place of welcome and care for those in need.

The word “palliative” derives from the Latin *pallium*, a cloak. Palliation means cloaking over, not addressing the underlying cause but ameliorating the effects.

Hospice has perhaps become thought of as solely a place of care. It is, however, much more than this and in essence is synonymous with palliative care. Both have a philosophy of care not dependent on a place or a building but on attitude, expertise, and understanding. The term “palliative care” was coined by Canadian urological cancer surgeon, Balfour Mount, as a term to apply hospice principles more broadly including within the hospital setting. More recently, the term *specialist palliative care* has been used to represent those professionals and services that concentrate on this area of health care as their main role and expertise, recognising that almost all health-care professionals provide elements of palliative care for patients as part of their practice (see Box 1.2).

Palliative care has been defined as:

> an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual [13].

Palliative care [13]:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;

- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

To this end palliative care is a partnership between the patient, carers, and a wide range of professionals. It integrates the psychological, physical, social, cultural, and spiritual aspects of a patient's care, acknowledging and respecting the uniqueness of each individual:

> You matter because you are you, and you matter until the last moment of your life. We will do all that we can to help you not only to die peacefully, but to live until you die [14].

End-of-life care

End-of-life care is the care needed by everyone as they approach the end of their lives. It is usually regarded as a focus on the last 6–12 months of life. It is of course difficult to define the last 12 months of life prospectively and much thought has been given to how indicators may help identify people. Figure 1.1 shows an example of how such indicators can be incorporated in to guidance to help identify appropriate people, which has been developed in Scotland.

The End-of-Life Care strategy (EoLCS) in England and Wales defined a pathway to optimise the quality of care in the last months of life (Figure 1.2) [7]. Many other countries have had similar initiatives.

All patients in the last months, weeks, and days of life need support from primary care. Many, because they are ill, will have contact with secondary care specialists including elderly care services and many of the more elderly patients (85 years+) (who, by 2030, will be 44% of the people that die every year in the United Kingdom) will live in care homes. Only a minority of those that die every year will need direct contact with specialist palliative care services.

The Gold Standards Framework (GSF) [15] provides a quality framework for end-of-life care in primary care and is explored in Chapter 2, *Palliative care in the community.*

Specialist palliative care

Specialist palliative care came into focus with the founding of St Christopher's hospice in London in 1967 by Dame Cicely Saunders. It was here that an approach that formed the basis for the role of specialist services was developed:

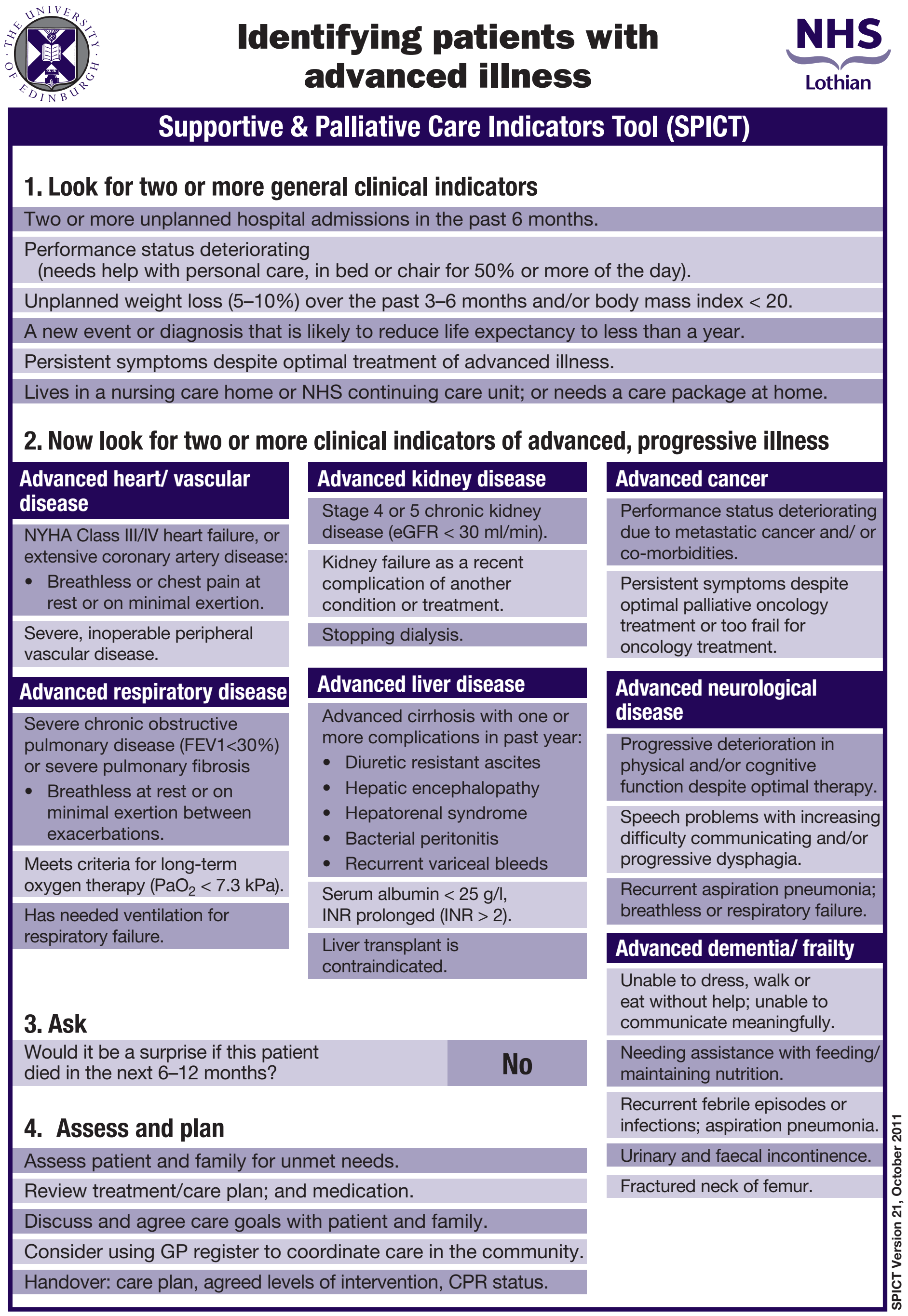
- High-quality care for patients and their relatives, especially those with complex needs.
- A range of services to help provide optimum care: whether the patient was at home, in hospital, or required specialist in-patient care.
- Education, advice, and support to other professionals.
- Evidence-based practice.
- Research and evaluation.

The subsequent, mostly unplanned, growth of specialist palliative care services has led to a wide variety of models of service provision, distribution and funding, with some areas, and therefore patients, being better served than others.

Issues in palliative care worldwide

Fifty-six million people die across the world each year, 80% of deaths occurring in developing countries. The world population is estimated to increase by 50% in the next 50 years and almost all of this increase in population will be in the developing world. In addition, there will be a huge shift in age of the population with a two- to threefold increase in population aged over 60 years in both the developed and the developing world. In the United Kingdom, it is estimated that by 2030 the percentage of deaths over 85 years of age will increase by almost a third to 44% of all deaths, around 255,000 people [16].

The Barcelona declaration on palliative care in 1996 [17], like the World Health Organization (WHO) in 1990 [18], called for palliative care to be included as part of every governmental health policy. Recent studies suggest that palliative care is integrated with wider service provision in only 15% of countries [19]. Although not enshrined in the Human Rights Act, most would agree that every individual has the right to pain relief. Inexpensive, effective methods exist to relieve pain and other symptoms. The *Life Before Death* campaign together with the International Association for the Study of Pain shows, in documentary films, the shocking and profound issues about pain management for people throughout the world, especially in the developing world [20]. Analgesics are inexpensive, and cost need not be an impediment to pain control. It is estimated that globally a hundred million people would currently benefit from the availability of palliative care. We are a long, long way from achieving this. Tens of millions of people die each year in unrelieved suffering [21].



Identifying patients with advanced illness

NHS
Lothian

Supportive & Palliative Care Indicators Tool (SPICT)

1. Look for two or more general clinical indicators

- Two or more unplanned hospital admissions in the past 6 months.
- Performance status deteriorating
  (needs help with personal care, in bed or chair for 50% or more of the day).
- Unplanned weight loss (5–10%) over the past 3–6 months and/or body mass index < 20.
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Persistent symptoms despite optimal treatment of advanced illness.
- Lives in a nursing care home or NHS continuing care unit; or needs a care package at home.

2. Now look for two or more clinical indicators of advanced, progressive illness

Advanced heart/ vascular disease

- NYHA Class III/IV heart failure, or extensive coronary artery disease:
  - Breathless or chest pain at rest or on minimal exertion.
- Severe, inoperable peripheral vascular disease.

Advanced respiratory disease

- Severe chronic obstructive pulmonary disease (FEV1<30%) or severe pulmonary fibrosis
  - Breathless at rest or on minimal exertion between exacerbations.
- Meets criteria for long-term oxygen therapy ($PaO_2 < 7.3$ kPa).
- Has needed ventilation for respiratory failure.

Advanced kidney disease

- Stage 4 or 5 chronic kidney disease (eGFR < 30 ml/min).
- Kidney failure as a recent complication of another condition or treatment.
- Stopping dialysis.

Advanced liver disease

- Advanced cirrhosis with one or more complications in past year:
  - Diuretic resistant ascites
  - Hepatic encephalopathy
  - Hepatorenal syndrome
  - Bacterial peritonitis
  - Recurrent variceal bleeds
- Serum albumin < 25 g/l, INR prolonged (INR > 2).
- Liver transplant is contraindicated.

Advanced cancer

- Performance status deteriorating due to metastatic cancer and/ or co-morbidities.
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment.

Advanced neurological disease

- Progressive deterioration in physical and/or cognitive function despite optimal therapy.
- Speech problems with increasing difficulty communicating and/or progressive dysphagia.
- Recurrent aspiration pneumonia; breathless or respiratory failure.

Advanced dementia/ frailty

- Unable to dress, walk or eat without help; unable to communicate meaningfully.
- Needing assistance with feeding/ maintaining nutrition.
- Recurrent febrile episodes or infections; aspiration pneumonia.
- Urinary and faecal incontinence.
- Fractured neck of femur.

3. Ask

Would it be a surprise if this patient died in the next 6–12 months? **No**

4. Assess and plan

- Assess patient and family for unmet needs.
- Review treatment/care plan; and medication.
- Discuss and agree care goals with patient and family.
- Consider using GP register to coordinate care in the community.
- Handover: care plan, agreed levels of intervention, CPR status.

SPICT Version 21, October 2011

Figure 1.1 The supportive and palliative care indicators guidance used in Lothian National Health Service (NHS), Scotland. (Reproduced with permission from NHS, available at www.palliativecareguidelines.scot.nhs.uk)

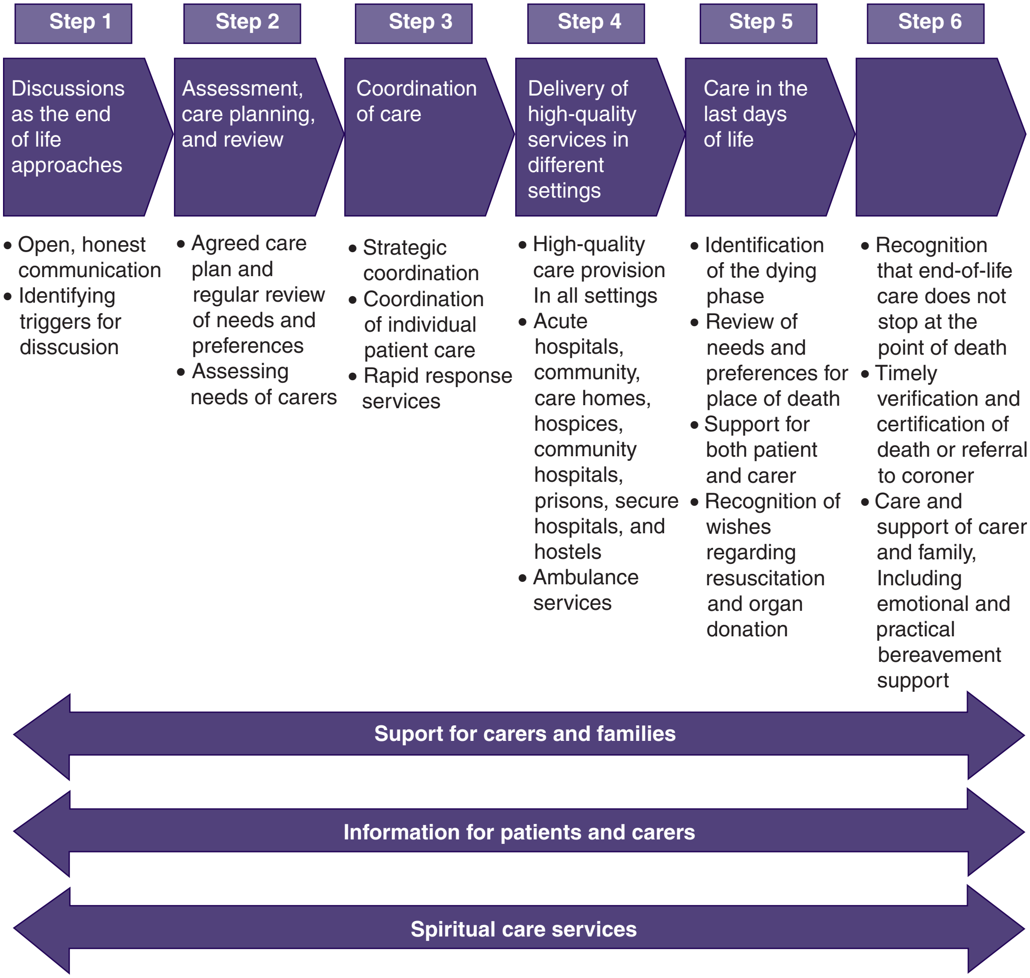


Figure 1.2 The end-of-life care pathway. (Reproduced from Reference 7)

The challenges for palliative care in developing countries

A multiplicity of challenges faces the development of palliative care globally, but the issues are more pronounced in the developing world for several reasons—principally, poverty, the ageing population, the high prevalence of smoking, and the increase in cancer and acquired immune deficiency syndrome (AIDS)-related deaths. It is estimated that in the Western world, deaths from cancer will increase by approximately 25% by 2020, but in China cancer deaths will increase by 145%, in India by 158%, in the Middle East by 181%, and in Africa by 149% [22]. The developing world has only 5% of the world's total resources for cancer control, although it must cope with almost two-thirds of the world's new cancer patients [23]. Globally the annual number of tobacco-related deaths is expected to rise from three million to ten million by the year 2025 [24]. Much more than half of this increase will occur in the developing world, three million in China alone. The developing world is currently suffering from an epidemic of lung cancer, making this cancer the most common worldwide. By 2015 approximately one million deaths in China will be from lung cancer.

Since the second edition of this book, the experience of HIV infection and AIDS has been transformed for those who can access antiviral medications. In 2009 some 33 million people were living with HIV/AIDS, of whom half are women, but during that year 1.8 million people died. It is estimated that deaths might rise to 6.5 million by 2030. Of those living with HIV/AIDS, 98% are in the developing world. The sociological effect of AIDS deaths in the developing world is catastrophic, especially in sub-Saharan Africa where the adult prevalence rate may be as high as 35% (although decreasing in some countries). AIDS affects those most likely to be breadwinners for the extended three-generation family and leaves many children orphaned. In 2009 there were estimated to be 16.6 million children orphaned through AIDS.

Availability of opioids

Under the international treaty, *Single Convention on Narcotic Drugs* [25], governments are responsible for ensuring that opioids are available for pain management. The 2010 report from the International Narcotics Control Board showed that opioids are still not widely available for medical needs [26]. More than 90% of the global morphine is used in ten industrialised countries. Over 80% of the world population will have insufficient analgesia, or no analgesia at all if they suffer from pain, including 5.5 million people with terminal cancer.

The main impediments to opioid availability, even in Europe, are government concern about addiction; insufficient training of health-care professionals; and restrictive laws over the manufacture, distribution, prescription, and dispensing of opioids [27]. There is also considerable prescribing reluctance on the part of the health-care profession, due in part to concerns about legal sanctions. This is made worse by the burden of regulatory requirements, the often insufficient import or manufacture of opioids, and the fear of the potential for diversion of opioids for nonlegitimate use. Most recently the Global Access to Pain Relief Initiative, a multiagency collaboration, is tackling the lack of access for the majority of people in need [28].

International observatory on end-of-life care

This is an invaluable resource for anyone wishing to learn more about global issues in palliative care. The website http://www.lancs.ac.uk/shm/research/ioelc provides research-based information about hospice and palliative care provision internationally, presenting public health and policy data, as well as cultural, historical, and ethnographic perspectives.

Unmet need and continued suffering in the developed world

The hospice movement and palliative care have come a long way in the past 45 years. There is a considerable body of knowledge and expertise, and services have grown enormously in number and character. There is, however, still a major unmet need. The majority of people are not living and dying with the comfort and the dignity that it is possible to achieve for most patients. Identified areas for improvement include:

- explicit recognition of patients in the last months, weeks, and days of life [4,8,9];
- management of pain in advanced cancer [27,29–33];
- management of other symptoms [29,33,34];
- information and support for patients and carers [35];
- attention to comfort and basic care for those dying in hospitals [9,36];
- the needs of patients dying from nonmalignant illness [37–43]; and
- the needs of patients who call for help out of "normal" working hours [44–47].

The major challenge for those who seek to improve the care for patients with advanced disease is to ensure that all health-care professionals consider palliative care an important part of their role and have adequate skills, knowledge, and specialist support to undertake it effectively. This is of crucial importance in the 70% of the week that occurs "out-of-hours" when patients are especially vulnerable to the deficits in health-care systems.

There are defined groups of patients who have poor outcomes, who underutilise specialist palliative care services, who have insufficient access to services and for whom service models need to develop to meet their needs in an appropriate way. Patients with illnesses other than cancer are considerably disadvantaged compared to those with cancer, and chapters later in this book discuss these issues in some depth and provide information on how to tackle them.

Health professionals in the world over recognise the fundamental human right to die with dignity. However, the notion of what constitutes a "good death" may vary considerably between and within cultures. While it has been shown that there are often greater similarities than differences between cultures when living and dealing with cancer [48], we know that it is more difficult for people from ethnically diverse communities to access or obtain information, support, and services that will meet their needs. Issues of communication, cultural diversity, appropriateness of information, organisational and staff attitudes, and discrimination are contributing factors across the spectrum of health and illness contexts, and having cancer is no exception to this experience [49–54]. For example, services such as counselling and psychological interventions in appropriate languages may not be available [48]. There may be difficulties in accessing self-help and support groups, Asian or African Caribbean wig types or prostheses and holistic pain control [54]. Greater understanding of cultural and individual variations in concepts of disclosure, patient autonomy, and patient-centeredness is needed. The extent to which these concepts may be ethnocentric and lack universality deserves wider consideration [49].

Compounding this disadvantage and poor quality of life is that people from diverse ethnic communities are more likely to be poor and have financial and housing difficulties. In addition, evidence, although limited by inadequacy of ethnicity monitoring, suggests that people with cancer from diverse ethnic communities have poorer survival than others [55]. In these conditions, it is not surprising that people from ethnically diverse communities with cancer consistently wish for [56]:

- more information about cancer, cancer treatments, and cancer care services;
- improved open communication and awareness about their condition;
- reduced feelings of stigma, isolation, and fear;
- greater control and choice in their care; and
- more effective care.

Migrant communities often have proportionately higher death rates from diseases not related to cancer, compounding their disadvantage in accessing palliative care. Gatrad and colleagues [57] suggest that realising high-quality palliative care for all will need fundamental changes on at least three fronts:

1. Tackling institutional discrimination in the provision of palliative care.
2. Progress in incorporating transcultural medicine into medical and nursing curriculums.
3. A greater willingness on the part of health-care providers to embrace complexity.

In doing these we shall develop a richer appreciation of the challenges facing people from minority communities in achieving a good end to their lives. These themes are explored further in Chapter 4, *Palliative care: choice, equality, and diversity.*

Enabling people to be at home

The EoLCS for England and Wales [7] has identified the key things that need to be in place to achieve the best possible care for people in the last months of life. These include:

- identifying people approaching the end of life;
- care planning;
- coordination of care;
- rapid access to care; and
- delivery of high-quality care by trained and competent practitioners in all service sectors.

These facets of care are discussed in depth in other chapters of this book, and Chapter 21, *Terminal care and dying*, focuses specifically on enabling people to die in the place of their choice.

Thomas [58,59] has developed seven standards (Box 1.3) to help primary care providers and teams improve their delivery of palliative care. Benefits have been demonstrated that include better communication and co-working and increased staff morale; however, the impact on patient outcomes especially achieving death in place of choice is less clear [60]. This is explored further in Chapter 2, *Palliative care in the community.* Communication with, and the quality of, out-of-hours primary care services is of critical importance in achieving the goals of care [44–47]. In more closed health systems such as the hospice programme in the United States, achievement of care and death at home is almost a prerequisite criterion of entry to the programme and therefore self-fulfilling; however, 80% of deaths in America are in hospital and only 7% die at home under hospice care.

Box 1.3 The seven “C’s”: gold standards for palliative care in primary care

***Communication*:** Practice register; regular team meetings for information sharing, planning and reflection/audit; patient information; patient-held records.

***Coordination*:** Nominated coordinator maintains register, organises meetings, audit, education symptom sheets, and other resources.

***Control of symptoms*:** Holistic, patient centred assessment and management.

***Continuity out-of-hours*:** Effective transfer of information to and from out-of-hours services. Access to drugs and equipment.

***Continued learning*:** Audit/reflection/critical incident analysis. Use of continuing professional development time.

***Carer support*:** Practical, financial, emotional, and bereavement support.

***Care in the dying phase*:** Protocol-driven care addressing physical, emotional, and spiritual needs. Care needs around and after death acted upon.

The principles of palliative care

Knowing how to approach patients with advanced illness is the first step in achieving effective care. Six key principles underpin effective, holistic care:

1. Consider the patient and their family/carers as the unit of care while respecting patient autonomy and confidentiality and acknowledge and encourage their participation.

2. Perform a systematic assessment of physical, psychological, social, and spiritual needs.

3. Communicate findings to the patient, providing information and support at all stages.

4. Relieve the patient's symptoms promptly: "*There is only today*."

5. Plan proactively and thoroughly for potential/anticipated future problems.

6. Use a team approach listening to suggestions and views and involving resources for extra support at an early stage.

What do patients and their carers need?

The uniqueness of each individual's situation must be acknowledged and the manner of care adapted accordingly. The essence of what patients and their carers may need is outlined in Box 1.4.

It should be clear from this that communication skills (see Chapter 6) play a fundamental role in achieving good palliative care and quality of life for the patient:

> Almost invariably, the act of communication is an important part of the therapy; occasionally it is the only constituent. It usually requires greater thought and planning than a drug prescription, and unfortunately it is commonly administered in subtherapeutic doses [61].

Achieving good symptom management

Twycross, among others, has done much to ensure an evidence-based, scientific rigor in palliative care [62]. The management of any problem should be approached as follows:

- Anticipation
- Evaluation and assessment
- Explanation and information
- Individualised treatment
- Re-evaluation and supervision
- Attention to detail
- Continuity of care.

Anticipation

Many physical and nonphysical problems can often be anticipated and in some instances prevented. Failure to anticipate problems and to set up appropriate manage-

Box 1.4 The rights and needs of patients and their carers

Patients have a right to confidentiality, pain control, and other symptom management and, wherever possible, to choose the setting of death and the degree of carer involvement. They also have a right to deny the illness.

Information

The patient has a need for sensitive, clear explanations of:

- the diagnosis and its implications;
- the likely effects of treatments on activities of daily living and well-being;
- the type and extent of support that may be required and how it may be addressed; and
- expected symptoms and what may be done about them.

Quality of life

The patient has a need for life that is as normal, congenial, independent, and as dignified as possible.

An individual's quality of life will depend on minimising the gap between their expectations and aspirations and their actual experiences. This may be achieved by:

- respect, as a person as well as a patient, from properly trained staff who see themselves as partners in living,
- effective relief from pain and other distressing symptoms,
- an appropriate and satisfying diet;
- comfort and consolation, especially from those who share the patient's values and beliefs and/or belong to the same cultural community;
- companionship from family and friends and from members of the care team;
- continuity of care from both the primary care team and other services;
- consistent and effective response to changes in physical and psychosocial discomfort; and
- information about support and self-help and other groups and services.

Support for carers

The patient's family or other carers have a need for support at times of crises in the illness and in their bereavement. These needs include:

- practical support with financial, legal, housing, or welfare problems;
- information about the illness (with the patient's consent) and the available support;
- respite from the stress of caring;
- involvement of carers in the moment of death and in other aspects of care;
- bereavement support; and
- special support where the patient's death may directly affect young children or where the patient is a child or adolescent.

Box 1.5 Applying an understanding of the natural history of a disease and psychosocial awareness to care planning

A 45-year-old woman has recently been found to have spinal metastases from her breast cancer. Potential issues that could be anticipated are:

- Pain—due to the boney origin; this may need nonsteroidal anti-inflammatory drug (NSAID), opioids, and radiotherapy.
- Constipation—start laxatives when opioid is prescribed.
- Spinal cord compression—examine neurology if unsteady or complains of numbness.
- If she has young children—may need help, practically and in telling the children.
- Work—may she need financial and benefit advice?
- Hypercalcaemia—check blood if nauseated or confused.
- Psychospiritual—how is she coping with the impact?

ment strategies (e.g., who should they call?) is a common source of dissatisfaction for patients [63]. Understanding the natural history of the disease with specific reference to an individual patient, awareness of the patient's psychosocial circumstances and identification of risk factors allows planning of care by the team. For an example of applying this in practice, see Box 1.5.

Evaluation and assessment

An understanding of the pathophysiology and likely cause(s) of any particular problem is vital in selecting and directing appropriate investigations and treatment. Deciding what treatment to use is based on consideration of the evidence of the mechanism of the symptom and of the treatment's efficacy, safety, and appropriateness in the situation. This is illustrated by the following specific examples:

- Sedation for an agitated patient with urinary retention is not as helpful as catheterisation.
- Antiemetics for the nausea of hypercalcaemia are important but so too is lowering the serum calcium (if appropriate).
- A patient who is fearful of dying may be helped more by discussing and addressing specific fears rather than taking benzodiazepines.
- Pain in a vertebral metastasis may be helped by analgesics, radiotherapy, orthopaedic surgery, transcutaneous electrical nerve stimulation, and acupuncture. A decision as to which to prescribe is made only by careful assessment.

Comorbidity is common and should always be considered. For example, it is easy (and unfortunately common) to assume that the pain in a patient with cancer is caused by the cancer. In one series almost a quarter of pains in patients with cancer were unrelated to the cancer or the cancer treatment [64].

The multidimensional nature of symptoms, such as pain, means that the use of drugs may be only one part of treatment. A holistic assessment is vital in enabling the most effective management plan. This includes eliciting the patient's concerns and focusing on their feelings.

Explanation and information

Management of a problem should always begin with explanation of the findings and diagnostic conclusions. This usually reduces the patient's anxieties, even if it confirms their worst suspicions—a monster in the light is usually better faced than a monster unseen in the shadows. Further information may be useful to some patients. A clear explanation of the suggested treatments and follow-up plan is important for the patient to gain a sense of control and security. Allow plenty of space for questions and check that what you meant to convey has been understood (see Chapter 6).

Some real examples:

Mr H, with advanced liver disease, was very anxious in the outpatient department. He told me he had developed a tender lump on his chest. On examination this turned out to be gynaecomastia, most probably, I thought, due to the spironolactone. With this explanation, and the relief of his anxiety, he chose to continue the drug rather than have recurrence of his ascites.

Mrs S looked worried and was angry. We discussed the scan results she had had 6 months earlier, before her chemotherapy and surgery. "So what does that mean?" she asked. "I'm afraid that means the cancer cannot be cured," I said. She dissolved in tears and said "Thank you doctor. I have been thinking this but no one would tell me."

Individualised treatment

The individual physical, social, and psychological circumstances of the patient and their views and wishes should be considered in planning care. For example, lymphoedema compression bandages may be unused unless there is someone available to help the patient to fit them daily.

Treatment options need to be shared with the patient and their perspective on choices be explored. For example, Mr K developed arterial occlusion in his leg. Because of his other symptoms, he was thought to have recurrent bladder cancer, but this was not confirmed by scans. He needed to consider whether to have an amputation. It appeared most likely that he would die from his disease within the next weeks to months. He decided that he would only have the amputation if he had 6 months or more to live and declined the operation.

Re-evaluation and supervision: be proactive

The symptoms of frail patients with advanced disease can change frequently. New problems can occur and established ones worsen. Interventions may be complex (many patients take more than 20 pills a day), and close supervision is vital to ensure optimum efficacy and tailoring to the patient.

Attention to detail

The quality of palliative care is in the detail of care. For example, it is vital to ensure that the patient not only has a prescription for the correct drug but also can obtain it from the pharmacy, have adequate supplies to cover a weekend, and understand how to adjust it if the problem worsens.

Continuity of care

No professional can be available for 24 h and 7 days a week, but patients may need support at all hours of the day. Transfer of information within teams and to those that may be called upon to provide care (e.g., out-of-hours services) is one way of ensuring continuity of care. Patient-held records, clear plans in nursing care records at the patient's house, team handover/message books, and formalised information for out-of-hours services [65] are all ways to achieve this.

Limits of symptom control

There is always something more that can be done to help a patient, but it is not always possible to completely relieve symptoms. Specialist advice should usually have been sought for help in the management of intractable symptoms. This extra support is in itself an important way of helping the patient.

In such situations an acceptable solution must be found to provide adequate relief of distress for the patient. For the management of a physical symptom and sometimes of psychological distress, this may be a compromise between the presence of the symptom and sedation from medications. It is hard for a team to accept suboptimal relief of symptoms, and discussions with the patient and the family may be very difficult. It is important for the team to remember the great value of their continuing involvement to the patients and their carers, to acknowledge how difficult the situation is, and not to abandon the patient because it is painful and distressing for the professionals:

> Slowly, I learn about the importance of powerlessness.
> I experience it in my own life and I live with it in my work.
> The secret is not to be afraid of it—not to run away.
> The dying know we are not God.
> All they ask is that we do not desert them [66].

Attaining quality in palliative care

The quality of palliative and end-of-life care is an area of increasing focus. A key challenge is the integration of palliative care alongside treatments of curative intent and in the care of many more patients [67]. Discussion of treatment benefits and burdens and of end-of-life choices is an important feature of quality in advanced disease. Guidance from the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom interprets the evidence base for achieving high-quality palliative and supportive cancer care [68] (see the key recommendations for primary care in Box 1.6) and has recently developed a Quality Standard for end-of-life care for adults [69]. The EoLCS in England and Wales has defined an array of quality outcomes markers [70]. Similar initiatives are in place in many countries across the world [71–74].

Box 1.6 Recommendations of the NICE guidance for Supportive and Palliative Care 2004, which are key for primary care

12: Mechanisms need to be implemented within each locality to ensure that medical and nursing services are available for patients with advanced cancer on a 24 h, 7 days a week basis and that equipment can be provided without delay. Those providing generalist medical and nursing services should have access to specialist advice at all times.

13: Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed and that the information is communicated within the team and with other professionals as appropriate. The *GSF* provides one mechanism for achieving this.

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

Source: Reproduced from Reference 68.

Box 1.7 Examples of palliative care quality assurance within a clinical governance framework for the primary care team and commissioners

Component of clinical governance	Example
A: Primary Care Team level	
Consultation and patient involvement	Are patients asked about their preferred place of death?
Clinical risk management	Is there a policy for the use of syringe drivers including rapid access to parenteral drugs?
Clinical audit	Are all patients taking morphine also prescribed appropriate laxatives?
Use of information about patient's experiences	How does the team reflect about those patients who die in hospital?
Staffing and staff management	Are there palliative care link nurses with performance reviewed job description?
Education, training, and continuing professional development	Does the team use up-to-date symptom management guidance?
B: Commissioners	
Organisational and clinical leadership	Are there designated managers, doctors, and nurses with lead responsibilities for palliative care?
Direction and planning	Is there a clear locality strategy to address identified gaps in services?
Performance review	Does the commissioner utilise its home death data and activity reports from specialist palliative care services to inform commissioning?
Patient and public partnership	How do cancer support groups work with the commissioner?

Quality assurance

The GSF for palliative care described above [15,58,59] is one possible method for assuring high-quality palliative care and is partially embedded in the quality and outcomes framework for primary care in England and Wales. The practical use of frameworks such as the GSF is discussed further in Chapter 2, *Palliative care in the community*. The use of a care pathway is another method of quality assurance, and two such pathways have been developed for care in the last days of life [75,76]. Standards for palliative care have also been developed for community hospitals and nursing homes.

Clinical governance systems are a key component of quality assurance, and examples relating to palliative care within this framework are shown in Box 1.7. In the future, commissioners may develop novel enhanced level services in palliative care, driving up the quality in areas of poor performance.

Audit of quality

In some countries, measurement and benchmarking of outcomes of specialist care is quite advanced [77], but none as yet measure quality or outcome in whole health systems.

Quality assurance frameworks such as the GSF and Dying Care Pathway are relatively easily audited with respect to goals of care. For example, a standard could be set by a commissioner or service or practice that the place of choice for death should be known for at least 80% of patients and a death at home should be achieved for at least 80% of those desiring this. Various measures of outcomes in palliative care has been developed, with a breadth of validation work [78,79]. Only two, however, have validation in primary care: the Palliative Care Outcome Scale [80] and the Cambridge Palliative Audit Schedule: CAMPAS-R [81]. Chapter 2, *Palliative care in the community,* explores the use of the After Death Analysis tool of the GSF.

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