

Palliative care services: meeting the needs of patients

Report of a Working Party 2007



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Contents

Members of the Working Party	v
Foreword	vii
Executive summary and recommendations	ix
1 The philosophy of palliative care	1
Palliative medicine: a unique specialty	1
The development of palliative care	1
Non-cancer palliative care	2
Current provision	2
Summary	3
Recommendations	3
2 The issues facing palliative care	5
Public attitudes, political action and service organisation	5
Non-cancer palliative care	5
Medical attitudes and practice	6
Clinical ethical issues	7
Current demand and future needs	10
Summary	11
Recommendations	11
3 The oncological experience and its application to other diseases	12
The development of palliative care for patients with cancer	12
Patterns of referral to palliative care	12
Best practice	12
Palliative care for patients with disease not related to cancer	13
Integrated care pathways	13
Drug treatments: benefits and burdens	15
Patients' and carers' perspectives and needs	15
Extending the oncological model to other specialties	15
Older people	15
Summary	17
Recommendations	17

4	Mental health problems in palliative care	18
	Psychological distress	18
	Specific treatments	18
	Advanced cancer	18
	Mental health support for people who are dying	19
	Palliative care for people with mental illness	19
	Palliative care for people with dementia	19
	Summary	21
	Recommendations	21
5	The organisation of palliative care and workforce provision	22
	Integrated and multidisciplinary care	22
	The Gold Standards Framework	22
	Workforce requirements	23
	Recommendations	28
6	Training	29
	Undergraduate training	30
	Postgraduate and specialist training	30
	Continuing professional development	31
	Recommendations	32
7	Research	33
	Recommendations	34
	Appendix 1: Witnesses	35
	Appendix 2: History of the development of palliative care	36
	Appendix 3: Palliative care and patients dying of non-malignant diseases	38
	Cardiac disease	38
	Respiratory disease	39
	Renal disease	40
	Neurology	41
	Human immunodeficiency virus	42
	References	45

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Foreword

Dying is a natural process which in a civilised society should be supported with good palliative care.

This statement from the All-Party Parliamentary Group on Dying Well encapsulates the philosophy underlying this report from the Royal College of Physicians, which comes at a time when concern to provide adequate care and support for the dying is growing. In 2004 the House of Commons Select Committee on Health *Fourth report on palliative care* and the *Guidelines for supportive and palliative care* (National Institute for Health and Clinical Excellence) were both published, followed in 2006 by the establishment of the All-Party Parliamentary Group and the introduction by the Department of Health of an End of Life Care Programme, with an End of Life Care Strategy to be launched this autumn. A Bill to establish a statutory obligation for the provision of palliative care introduced by Baroness Professor Ilora Finlay is currently going through Parliament. End of life is also one of the key workstreams in Lord Darzi's recently announced NHS review. All these initiatives highlight the timeliness of this report.

Palliative medicine has been recognised as a specialty by the Royal College of Physicians since 1987. It has continued to grow in size and influence since that time, providing clinical leadership to multidisciplinary teams. Originally born out of the need to improve the quality of life for people with advanced cancer and with its roots in the hospice movement, the relevance of the specialty to any patient with advanced, progressive illness requiring specialist input to improve their quality of remaining life is increasingly recognised, and is one of the main themes of this report.

A consequence of this underlies another theme of the report: that palliative care is relevant for most clinicians, not just palliative medicine specialists. The skills and knowledge required to give clinical palliative care during the final phases of a disease and to identify the point at which patients pass beyond remedy should be part of the training of all doctors. The advances in medicine which extend the lives of many patients make this increasingly important. More fundamentally, a change in attitude is required for both clinicians and the public away from perceiving death as failure and towards seeing it as a natural part of life and an inevitable part of the trajectories of many currently incurable diseases. This report is an important step in that process and I warmly commend it to you.

How a society cares for its dying is one indicator of its health. Locally supported voluntary and charitable hospices have filled the gap in national provision; it is now time that the provision of clinical palliative care should be centrally supported with sufficient trained clinicians and adequate funding. The financial implications of this are significant, and the report makes recommendations for national funding and for workforce numbers.

October 2007

Professor Ian Gilmore
President, Royal College of Physicians

Executive summary and recommendations

Executive summary

All patients who are suffering and dying should have equivalent access to palliative care. Everybody should have the opportunity for a good death, with management of symptoms and psychological, social and spiritual support. Access to palliative care services currently is inadequate and inequitable, with unacceptable variation in care geographically, across demographic groups and across diagnoses. Services for patients who are dying of non-cancer-related diseases are lacking.

Health professionals' behaviour towards people who are dying and their attitudes to death and dying need to change. Few of us are comfortable with the thought of our own mortality, and we instinctively shy away from those who are approaching their own deaths. The end of life is as important as the beginning, but scarce attention has been paid to it, except for patients with cancer. The success and growth of the hospice and palliative care movement is great testimony to the importance the public places on high-quality care towards the end of life.

In society, and among healthcare professionals, death can be perceived as a failure, and emphasis on cure may lead to inappropriately late referrals when patients have distressing symptoms and complex care needs. In the future, however, a move to models of chronic disease management will be inevitable and essential for delivery of effective, appropriate and timely care to an ageing population. Such models must recognise that the trajectories of different diseases differ, and the timing and nature of palliation must reflect this.

Funding for palliative care services is unsatisfactory, with the National Health Service (NHS) contributing only about 30% of the costs of specialist palliative care. This reliance on the voluntary sector, and charitable funding, exacerbates inequalities and has led to poor planning and overall integration of services. Sustainable and adequate core funding from the NHS is essential not just to support services but to ensure strategic planning and cohesive coordination of all types of provision for patients in need of palliation and end-of-life care. This can be assured only if there is explicit accountability for specialist provision at the board level of all commissioning structures and providers.

Research into the efficacy and cost effectiveness of many palliative care interventions is inadequate. Better basic research is needed into the development of new treatments for symptom control, as is research into models of care for provision of integrated end-of-life services. Barriers to research include difficulties with undertaking randomised controlled trials in this vulnerable group, the lack of commercial incentives to develop new drugs and difficulties with conducting research in small independent clinical units. Enhanced NHS funding for translational and clinical research, as well as the delivery of services, is needed to ensure that palliative care is evidence based.

One strategy to improve end-of-life care is to use integrated care pathways not just for the dying (for example, the Liverpool Care Pathway and the Gold Standards Framework) but also to identify specific 'triggers' along a disease care pathway that initiate specific interdisciplinary palliative care assessment and intervention. This must go hand in hand with a clear understanding of the ethics and duties that underpin changes in emphasis from curative to palliative strategies. To identify

disease triggers and develop such pathways is challenging, as the practical difficulties of research in end-of-life care are considerable and the evidence base for palliative care interventions is patchy. National and regional audits of palliative care and research into specific models of care therefore are needed as a priority to determine how best to deliver effective palliative care to all specialties in primary and secondary care. Integrated care pathways may be the effective tools to bring about change and to audit and standardise the quality of care being delivered. Clinical studies also are needed to elucidate some of the areas of uncertainty in the control of symptoms.

All specialties must address the palliative care needs of their patients and the consequent resource and training implications for their disciplines. Specific training needs should be identified and incorporated into curricula for higher specialist training. Generic palliative care should be a core part of training for all healthcare professionals and a requirement for continuing professional development (CPD).

The needs and demographics of the population are changing, and most patients would prefer much of their care to be provided in the community and to die at home. Difficulties in delivering effective palliative care in the community are exacerbated by a number of factors. These include lack of expertise and human resource, ineffective coordination and communication between service providers, inadequate integration of healthcare and social care services and inconsistent community provision of the necessary support and out-of-hours care.

Specialists in palliative medicine will continue to have a central role in strategic planning and the development of services, promoting integrated and collaborative models that cross traditional organisational boundaries and offer effective seamless care. They will provide support and training for clinicians in a wide range of disciplines and across a range of healthcare services, advising on clinical decision making at transition points towards the end of life. In addition to practising at the bedside, they will stimulate and support research into improved management of symptoms and systems of care.

The provision of truly holistic and effective end-of-life care requires the contribution of a number of healthcare and social care disciplines. Within this interdisciplinary care, medicine is of fundamental importance. Physicians therefore need access to education and support in a philosophical approach that is unfamiliar to many, in addition to the technical expertise that is necessary to manage the diverse aspects of suffering. Specialist palliative medicine physicians are needed to develop and sustain this approach in others as the foundation of good end-of-life care and to manage patients with the most complex needs. Although there is a need for education and training for all groups of healthcare professionals, addressing the shortage of specialists trained in palliative medicine is particularly important.

RECOMMENDATIONS

Service development

- 1 All patients who are suffering and dying should have equitable access to palliative care services. Increased provision of palliative care services is needed in the United Kingdom (UK), both in the community and at the levels of secondary and tertiary care, to abolish the disparity in provision for patients with non-malignant diseases and cancer, as well as regional inequalities.
- 2 Increased core NHS funding is needed so the service is not dependent financially on charitable giving.

- 3 Central planning and commissioning should focus on integrated care across primary, secondary and tertiary healthcare and social care interfaces, with emphasis on cross-agency working and on making access for patients and carers simple and reliable. Structures for coordination need to reflect this.
- 4 Boards of all commissioning structures and healthcare and social care providers should be explicitly responsible for general and specialist provision and implementation of the national strategy, with requirements for annual reporting.

Service provision

- 1 Palliative care services should accommodate diverse cultures and lifestyles; physical symptoms and the psychological, spiritual and social aspects of care are of equal importance and should be managed appropriately. Development of these services should encompass the current emphasis on patient choice within the framework of the law, and the differing beliefs and needs of ethnic groups must be taken into account.
- 2 Referrals often are made late, when patients have multiple problems and significant distress. Clinicians must recognise that end-of-life care does not mean that someone is going to die imminently but that the approach to their care should change. A proactive approach should be adopted to ensure that patients and their families have timely and appropriate care. It is important to identify triggers to ensure that palliative care treatments or referrals are initiated early and appropriately and to use systems of communication that facilitate continuity of care between doctors working in shift patterns.
- 3 Clinicians should begin with the general identifier that end-of-life care should start when it would no longer be a surprise if the patient should die in the next year.
- 4 All clinicians who deal with people who are dying need to have a clear understanding of how to discuss, facilitate and make available the proper freedoms and entitlements of their patients and their loved ones and how to engage the distress that comes with incurability and impending death.
- 5 When the dying phase is recognised, the use of integrated care pathways for the dying, such as the Liverpool Care Pathway, should be encouraged for patients with conditions of any disease group not confined to cancer.
- 6 A local register should record patients identified as needing palliative care in order to allow planning, review and coordination of services. Information therefore should be available to all general practices and should be disseminated to hospices and secondary and tertiary settings. This will require the appointment of nominated coordinators with administrative and information technology (IT) support and routine connection of all hospices to NHS.net.
- 7 Older people who die in hospital should become a priority of care for geriatricians in association with colleagues in palliative medicine. Geriatricians are well placed to use the multidisciplinary approach to provide holistic care to address the multiple symptoms of their patients, whatever their underlying diagnosis. Palliative care should become an important part of the training for geriatric medicine and may need to be given alongside training of specialist palliative medicine physicians.

- 8 Professionals in all settings and across all specialties should be aware of and able to address the palliative care needs of people with dementia and other mental health issues.
- 9 Emergency mental health support is essential. This will require the provision of additional training.

Workforce

- 1 Sufficient trained individuals are required to carry out needs assessments for each identified patient and their carers and to generate a comprehensive care plan.
- 2 Sufficient appropriately trained staff are needed to deliver the care. Particular difficulties are encountered with out-of-hours care. Interprofessional cooperation and communication must be improved to ensure efficient continuity of care.
- 3 The number of whole-time equivalent (WTE) consultants needed to manage patients with cancer and non-cancer palliative care is estimated to be one in 160,000 of the population. This equates to 376 WTEs for the UK (344 WTE in England, Wales and Northern Ireland) and is higher than the 271 existing WTE identified in the RCP's census of consultants in 2006. Overall, 83% of specialist trainees are women, and many wish to train part time, which exacerbates the shortfall in new consultants to fill vacant posts and expand the service. A significant expansion of training posts has just been announced for the short term. Expansion of consultant posts is required.
- 4 The career aspirations and training needs of the large number of non-consultant career grade (NCCG) personnel who work in palliative medicine should be addressed. Personnel at NCCG comprise 30% of the membership of the Association for Palliative Medicine, and many are unhappy with their career opportunities and working environments.
- 5 Many consultants are working single handedly in isolated small units. Singlehanded posts should be discouraged, and posts should be shared across small units or formal networks of care established. All palliative medicine clinicians working in charitable hospices should have NHS contracts, with the associated terms and conditions of service, including the need for annual appraisal and access to study leave and CPD.
- 6 Statutory funding should be provided to address the national shortfall in funding and workforce for these posts.
- 7 Working arrangements between different members of the multidisciplinary team (MDT) across primary and secondary care need to be strengthened, with closer liaison between community colleagues and hospital services, particularly out of hours. Specialist social workers should be empowered to arrange community packages of care for their patients directly or to liaise more closely with community colleagues to deliver seamless care.
- 8 Significant shortfalls exist for many other healthcare professionals in the MDT. These deficiencies need to be identified by primary care trusts and addressed through commissioning processes.

Training

- 1 Palliative care services are interdisciplinary, with care delivered by a MDT. Generic palliative care should be a core part of training for all healthcare professionals, with knowledge and skills maintained and kept up to date.
- 2 From foundation training onwards, each medical and surgical specialty should address palliative care provision within the specialty and ensure that specialist curricula and CPD reflect the required knowledge and skills. This must go hand in hand with a clear understanding of the ethics and duties that underpin the change from curative to palliative strategies, including the appropriateness of and justifications for withholding or withdrawing treatments and the safety of opioids and sedatives when prescribed competently at the end of life.
- 3 The postgraduate diplomas of the Royal Colleges of Physicians, Surgeons, Radiologists and General Practitioners should include specific testing on identified palliative care competencies for each specialty.
- 4 Awareness of the requirements for all grades of palliative medicine physicians to undergo CPD and appraisal needs to be raised among managers in the charitable sector. Support must be forthcoming in routine arrangements for cover for absences and financial support.
- 5 The role of specialty palliative medicine physicians in the future will include leadership in strategic planning and development of services, support for education and training across a wide range of healthcare professionals and provision of expertise in ethics and clinical decision making, as well as delivery of specialist palliative care to individual patients with complex needs. Workforce planning, CPD and consultant job plans must reflect this.

Research

- 1 Research into the efficacy and cost effectiveness of many palliative care interventions is inadequate. Research is needed to determine an evidence base for best practice and to define the most effective elements of current practice. This will require the participation of many NHS clinical units and hospices, as well as the facilitation of multicentre clinical studies, including randomised controlled trials.
- 2 Better basic research is needed into the techniques of palliative care, the effectiveness of differing treatments, the development of new treatments for symptom control and their acceptability and benefit to patients.
- 3 Provision for academic posts in palliative medicine is very limited. This must be rectified in order to progress research and research training in the specialty.
- 4 Research into models of care should be conducted to determine how palliative care services should integrate with other specialties to provide care. This will provide evidence to support the manpower and resource issues associated with an expansion of specialist palliative care practice into non-malignant diseases.
- 5 National and regional audits of the experiences of patients who are receiving palliative care and the services available to them are needed. Audits should incorporate the care of patients who are dying across a range of medical diagnoses. Information from national comparative audit will lead to improvements in care, in the same way that national audits of the in-hospital care of patients after stroke has resulted in significant improvements in their care.

- 6 In order to improve access and equity of provision, research is needed into the development and evaluation of new approaches to the clinical assessment of need for palliative care in the context of uncertain prognosis in a range of diseases and care settings. Identification of clear triggers for referral throughout the course of an illness, where there is evidence of benefit from palliative care services, is important.
- 7 The lack of commercial incentives for the development of new pharmacological interventions in palliative medicine is a threat to the exploitation of scientific advances to improve treatment. Enhanced public and voluntary sector funding for translational and clinical research, as well as continued health service research, is needed to alleviate this barrier to progress in the field.

1 The philosophy of palliative care

Palliative care is an approach that improves 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.

(World Health Organization (WHO), 2002)¹

Palliative medicine: a unique specialty

1.1 Palliative medicine is a unique specialty that finds expression as a philosophy of care rather than a set of technical skills or a body system. It enables the patient and family to respond to suffering in a climate of uncertain prognosis and deteriorating health and helps them to resolve practical, psychological and spiritual matters. Conversely, other modern specialist practice may see pathologies rather than patients and lose the caring component of medicine, particularly for those with chronic or progressive diseases. There is a risk that palliative care could default into a series of competencies directed only at technical control of symptoms, but the new focus on a patient-centred approach creates an opportunity for a philosophical shift back to consideration of the global nature of disease in a patient and their family.

1.2 Finlay and Jones² have described three separate components of palliative care:

- ▶ a palliative approach to medical practice as a whole, which, where appropriate, should be common to all clinicians
- ▶ palliative interventions, e.g. interventions for symptom control
- ▶ specialist palliative care requiring the input of a medical specialist.

1.3 Provision of this type of care is beyond the scope of the individual practitioner or a single discipline; team interdependence is at the core of palliative medicine, and consideration of service provision must be made in this context. Good end-of-life care is both complex and multidisciplinary.

The development of palliative care

1.4 Following the pioneering work of Dame Cicely Saunders and the establishment of St Christopher's Hospice in London in 1967, the United Kingdom (UK) has led the development of modern palliative care. A further milestone in the UK was the Royal College of Physicians (RCP)'s recognition of palliative medicine as a medical specialty in 1987. A history of the development of palliative care is given in Appendix 2.

1.5 Palliative care is unusual among medical specialties in that much of the service has developed outside the National Health Service (NHS) in the voluntary sector and funded by charitable organisations. Local and charity-based provision, however, has led to real inequalities in service provision – both in quality and quantity. Affluent areas of the country with less clinical

need are better provided for than less affluent areas with more clinical need. Douglas has made the perceptive criticism that: 'the hospice movement is too good to be true and too small to be useful'.³ Clark has commented '...questions of equity have been thrown into relief by the success of hospice services, often working within the independent sector, but where coverage can be limited.'⁴ This situation needs to be addressed.

Non-cancer palliative care

1.6 The historical perception that palliative care was only for people who are dying and that there was no relation with the active phases of disease management has changed. For example, the nature of acquired immunodeficiency syndrome (AIDS) early in the epidemic necessitated that palliation, prophylaxis and attempts to cure occurred simultaneously.⁵ The role that then emerged for palliative medicine was to support patients in circumstances of extreme uncertainty, helping them see that hope and cure are not synonymous and that quality of life could be achieved and control restored in a productive way. The idea of setting goals in palliative care began to include aggressive short-term treatments and interventions with specific objectives.⁶

1.7 Palliative care increasingly has encompassed non-malignant conditions,^{7,8} although it came late to the non-cancer specialties. The ethical imperative for generic palliative care is well established, but few services were involved significantly before 2000. Essentially, the argument is one of justice: need, not pathology, should be the underlying criterion for access to palliative care.⁹

Current provision

1.8 Comprehensive palliative care services are interdisciplinary, with care provided by hospital and community teams and daycare and outpatient facilities, usually in a hospice. Despite an increased priority being placed on access to and the development of palliative care over the past 10 years, services remain patchy: the best is excellent, the worst is substandard or non-existent. The House of Commons Health Committee, in its inquiry into palliative care, highlighted these inequalities by diagnosis, geographical area and patient demographics – particularly age and ethnicity.¹⁰ As an example, the Northern Cancer Network requires 30% above the average palliative care services but has only half the average number of beds, whereas Surrey needs 20% below the average but has one of the highest ratios of beds to population in the country.¹¹

1.9 Were it not for local visionaries and local communities, palliative care might not exist at all in the UK and the hospice movement might not have flourished. Inequalities in provision historically are due to the large role that the voluntary sector has played. It is easy with hindsight to criticise this; however, 80% of specialist palliative care beds are in independent hospices, with the NHS contribution to funding averaging just more than 30%. Of the 172 units in England, 132 are outside the NHS. In 1999, the average distribution of palliative care beds was 51 per million population but varied from 34 per million population to 62 per million population across the country. The number of community-based clinical nurse specialists per million population was 21, but this varied regionally from 15 to 30.¹²

1.10 The Working Party welcomes the national End of Life Care Strategy and urges every effort to reduce inequities in access, increase provision and allow cohesive and coordinated development of services. Central planning and commissioning should focus on integrated care across the primary, secondary and tertiary healthcare and social care interfaces, with an emphasis on cross-

agency working to make access for patients and carers simple and reliable. Structures for coordination need to reflect this.

1.11 Palliative care remains heavily weighted towards patients with cancer, yet provision is far from satisfactory even for the 155,000 people who die from cancer every year: only 3,250 hospice beds are available, and 2,489 of these are supplied by the voluntary sector. Although 95% of patients who use hospice or palliative care have cancer,¹³ the National Council for Palliative Care has estimated that 300,000 people die each year from progressive non-malignant diseases;¹⁴ and for example, half of all patients diagnosed with motor neurone disease die within 25 months of diagnosis,¹⁵ yet a survey carried out in 2005 found that only 39% of patients who died from motor neurone disease were referred to specialist palliative care services (Motor Neurone Disease Association, tracking survey 2005, unpublished data available from MNDA, www.mndassociation.org).

1.12 The service clearly should be geared towards need and not diagnosis. Many patients who have heart, lung, renal, neurological and other problems could benefit substantially from the palliative care approach, but services currently are compromised by limited availability. Availability can be assured only if there is explicit accountability for specialist provision and implementation of the national End of Life Care Strategy at the board level of all commissioning structures and healthcare and social care providers for palliative care, with requirements for annual reporting.

SUMMARY

Access to palliative care services is inadequate and inequitable, with unacceptable variation in care geographically, across different demographic groups and across diagnoses. Services for patients dying of diseases not related to cancer are lacking. All patients who are suffering and dying should have equivalent access to palliative care. Everybody should have the opportunity for a good death, with control of symptoms and practical, social, emotional and spiritual support.

Funding for palliative care services is entirely unsatisfactory, with the NHS contributing only about 30% of the costs of funding for specialist palliative care. This excessive reliance on the voluntary sector, and charitable funding, exacerbates the inequalities, favours the model of standalone hospice buildings and has led to poor planning and overall integration of services. Sustainable and adequate core funding from the NHS is essential to allow support of palliative care services and strategic planning for the cohesive development of services across the country. Palliative care services cannot continue to be funded primarily through charitable sources.

RECOMMENDATIONS

All patients who are suffering and dying should have equitable access to palliative care services. Increased provision of palliative care services is required in the UK, both in the community and at the levels of secondary and tertiary care, to abolish the disparity in provision for patients with non-malignant diseases and cancer, as well as regional inequalities.

Increased core NHS funding is needed so that the service is not dependent financially on charitable giving.

Central planning and commissioning should focus on integrated care across primary, secondary and tertiary healthcare and social care interfaces, with emphasis on cross-agency working and on making access for patients and carers simple and reliable. Structures for coordination need to reflect this.

Boards of all commissioning structures and healthcare and social care providers should be explicitly responsible for general and specialist provision and implementation of the national strategy, with requirements for annual reporting.

2 The issues facing palliative care

Public attitudes, political action and service organisation

2.1 Palliative care seems to be at a crossroads. There is now a real expectation that death should be managed properly, with consideration being given to the patient's wishes in the context of physical symptoms and the psychological, spiritual and social aspects of care. Furthermore, family and carers have to be part of the network that gives and receives care. It is recognised that many patients currently have a bad death – often in the wrong place. This has to be seen in the context of a patchy palliative care service and a very small consultant workforce; yet despite pressure on budgets and sustained campaigns for euthanasia, there does seem to be political will in favour of better care for people who are dying and for palliative care.

2.2 Recent parliamentary and related activity includes:

- ▶ publication of the House of Commons Health Committee's fourth report on palliative care in 2004, which made specific recommendations on funding, removing some of the 'disease bias' away from cancer, raising the skills of healthcare staff and addressing inequity of provision¹⁰
- ▶ publication of the National Institute for Health and Clinical Excellence's (NICE) guidelines for supportive and palliative care in 2004,¹⁶ which made recommendations to improve the services and quality of life for adult patients with cancer; these included the need for a range of physical, emotional, spiritual and social support for patients and their families and carers but the publication failed to recognise that many other distressing conditions would benefit from a palliative care approach
- ▶ regulatory changes around the use of opioids after publication of the fourth report of the Shipman Inquiry¹⁷
- ▶ the establishment of an all parliamentary group on 'dying well' in 2006¹⁸
- ▶ the introduction of the End of Life Care Programme by the Department of Health in 2006¹⁹
- ▶ the House of Lords introduced bills on the one hand with the intention of legalising physician-assisted suicide and euthanasia (Lord Joffe between 2002 and 2006) and on the other hand attempting to establish a statutory obligation for the provision of palliative care (Baroness Professor Iora Finlay, 2007).

Non-cancer palliative care

2.3 Given that the holistic needs of patients are influenced relatively little by pathology, many patients with conditions not related to cancer should qualify for specialist palliative care. However, delineation of those conditions that would benefit, knowing when to involve palliative care and, particularly, assessment of prognosis are fraught with difficulty and uncertainty. Furthermore,

there are concerns about service capacity, particularly as many non-malignant diseases have longer time courses and less predictable trajectories. Nevertheless, a recent review of the subject concludes: 'palliative care is not to be regarded as a luxury, an optional extra.'

2.4 Triggers for accessing palliative care that are solely related to clinical estimates of individual patients' survival are likely to fail because of the uncertainty of prognoses in most chronic life-threatening conditions. The pragmatic and rational approach that seems to be emerging is to define what is meant by the end of life, which is being taken as the time when one would not be surprised if the patient were to die in the next year.²⁰ Although the point at which a person enters the end-of-life phase should trigger assessment of palliative care needs, other points in the course of an illness have been identified as triggers in patients with cancer and may also be appropriate for other diagnoses. These include: around the time of diagnosis, commencement or completion of treatment, disease recurrence or relapse, the recognition of incurability and the point at which the dying process is diagnosed.²¹

2.5 Screening, with a self-report assessment tool, is another approach to identifying a point when patients require detailed assessment of their palliative care needs. At least 15 such questionnaires have been developed, with the aim of identifying patients' current distress. Two of these, the Distress Management Tool and the Sheffield Profile for Assessment and Referral to Care (SPARC), seem to cover all generally recognised domains of distress, although none has been adequately evaluated in terms of clinical validity or utility.²²

Medical attitudes and practice

2.6 With therapeutic advances, medicine is seen increasingly as a curing profession, with the caring aspects of medical practice taking a subsidiary role and death being perceived as a failure. Any recognition that people who are dying should be managed well thus has not been matched with a proportionate rise in the skills and attitudes of doctors in primary or secondary care. In his article on 'The inhumanity of medicine',²³ David Weatherall criticises high-tech care at the expense of the support of very sick people and refers to a:

deficiency of the basic skills of handling sick people as humans, poor communication, lack of kindness, thoughtlessness and, in short, all the facets of good interpersonal relationships that society has a right to demand of its doctors.

2.7 In a critical review of palliative care provision, Clark contrasted the medicalisation of dying in a palliative care setting with the prevarication about and resistance to death in the wider medical system.²⁴ He concludes that:

the challenge for palliative physicians is no different to that facing their counterparts elsewhere in medicine: how to reconcile high expectations of technical expertise with calls for a humanistic and ethical orientation for which they are largely unselected and partially trained.

2.8 This is even more of a challenge for the members of a complex multidisciplinary team (MDT) working in the hospital, community and hospice. Their influence is spread too thinly, and their expertise is often required urgently for uncontrolled physical symptoms and distress, because advice is sought too late or at times when it is not readily available.

2.9 These difficulties are exacerbated by the widespread practice of full-shift working for junior doctors, out-of-hours cover by hospital at-night teams and variable out-of-hours cover by

general practitioner (GP) services. Special attention needs to be paid to detailed and accurate handover of treatment plans when the clinical picture may be changing rapidly. Continuity of care is also a casualty of work patterns that favour organisations and not patients, as the opportunities to build caring relationships with patients and families are lessened with frequent changes in clinical teams.

Clinical ethical issues

2.10 The need for practical, effective and robust understanding of the ethical foundations of care at the end of life is now acute for all clinicians. It is part of daily practice for palliative medicine specialists who are managing complex family networks and rapidly changing therapeutic climates. Palliative medicine physicians are familiar with the need to balance the benefits and burdens of treatments when the imperative is to relieve suffering alongside curative treatment and when it is no longer possible to reverse a pathology without an unacceptable cost to quality of life or the treatment is simply no longer effective. Nevertheless, even with training in communication, and to some extent in ethics, conversations about withholding or withdrawing treatments and the dying process are becoming more difficult to resolve satisfactorily. In a society that seems to be increasingly confused about medicine's role, palliative measures – especially opioids and sedatives – are assumed by patients, families and many colleagues to bring about an earlier death.

2.11 All clinicians who care for patients with life-limiting illness need training and support in three prominent and interconnected areas:

- ▶ how to engage with the increasing societal weight given to the ideas and language of 'rights'
- ▶ how to correct the misinformation, confusion and anxiety that accompanies the prescribing of opioids and sedatives to patients who are dying
- ▶ how to be clear that the appropriate withdrawal of life-sustaining treatments as good medical practice is entirely distinct from specific and active means of ending life by prescribing or administering lethal drugs.

2.12 Confusion between the popular ideas and language of 'rights' and their ethical framework and legal application is protean. Put most simply, there are two distinct types of right – liberties and entitlements:

- ▶ Liberties are decisions and actions (personal goods) that a person is free to enjoy, which may be personally harmful but must not harm others. A person's liberty, or autonomy, is always limited, therefore, by the risks of harm to others or the equivalent liberties of others, particularly vulnerable people. The law sets this limit according to the risk to the 'common good'. Three examples show this gradation from purely personal good/harm through to a manifest and mortal risk to others: refusal of treatment is an absolute freedom for a capable adult;²⁵ smoking remains legal, but is increasingly limited; and suicide or its attempt, although not criminal, triggers active health measures, and it is illegal to provide assistance.²⁶
- ▶ Entitlements are what society agrees are collective goods to which anyone is entitled if appropriate. These cannot, by definition, be harmful, and society has a duty to

provide them but only according to need and not demand. Basic entitlements such as healthcare and education have statutory frameworks and correlative professional duties; moral entitlements like expecting truthfulness or courtesy are merely reasonable features of citizenship in a civilised society.

2.13 Firstly, the increasing weight society has given to the ideas and language of 'rights', although an increasingly unassailable fact in our society, is not without difficulty. It is a requirement of our duty of care to consult, respect and include patients and, in some circumstances, their advocates in clinical decision making. The law, codified in the Mental Capacity Act 2005, is also clear that a capable person is the judge of what would constitute his or her own best interests.

2.14 However, freedoms, entitlements, needs and wants frequently are conflated or given illegitimate legal force by the media, distressed patients and pressure groups. With incurable diseases, this may translate into unrealistic expectations of cure and the public impression that patients do not die of diseases but because their doctors stop treatment.²⁷ By extension, doctors often are led to feel that they bear the entire responsibility and culpability for an illness, its consequences, any suffering and the dying process. Withholding or withdrawal of treatment is seen as or claimed by some to be no different to issuing a lethal prescription or killing the patient. This idea that rights are limitless, equivalent and uniformly good for an individual and society offers some explanation for the paradoxically coincident rise in demands for treatment no matter how futile and in demands for the active, intentional termination of life, such as euthanasia or physician-assisted suicide. A comprehensive discussion of the problems of rights discourse is given by Penney Lewis.²⁸

2.15 Such confusions compound the second issue: the misinformation, confusion and anxiety that accompanies prescribing in people who are dying. This needs urgent clarification. Bodkin Adams in 1957 used the doctrine of double effect (DE) successfully to justify the administration of what was probably a fatal dose of narcotic to a patient from whom he was to inherit on the grounds that he was controlling her symptoms.²⁹ This gave a 'legal factual weight' to the fallacy that morphine kills as a matter of course in palliative care. As a consequence, some doctors, the public (including lawyers) and philosophers assume that, because morphine is an addictive killer, adequate control of pain can be achieved only at the expense of shortening life. When prescribed appropriately, morphine is safe over a wide range of doses. Competent clinicians use proportionately small repeated doses titrated to the individual, usually with concomitant analgesics and always with the aim of achieving relief without harm.

2.16 These misunderstandings have also distorted research methods on end-of-life decisions and further confused the debate on euthanasia and end-of-life care in general. For example, doctors have worrying fallacious conflicts: 'to treat the pain or distress "knowing" that I will shorten life' or 'to leave the patient suffering unnecessarily to avoid "killing"', together with wrong moral double binds such as 'In order to kill the pain, I may well (have to) kill the patient' and 'Because I have given opioids to a dying person, I must have killed patients already.' This in turn restricts appropriate prescribing and a truthful distinction between good palliation and euthanasia that is masquerading as symptom control. These problems have been reviewed recently by George and Regnard.³⁰

2.17 A survey of Members and Fellows of the RCP in 2004 showed that 71.3% of 5,111 respondents (27.9% response rate) were opposed to changing the current law.³¹ Euthanasia is

not part of palliative care philosophy. It undermines and opposes the principles that underlie the provision of good palliative care, including the importance of a holistic approach, keeping faith with all patients and colleagues that doctors care for patients explicitly without shortening life and keeping faith with themselves in order that they do not develop distorted perceptions of illness, suffering or treatment so that patients may express their deepest fears and feelings safely without fear of misinterpretation or harm. Evidence supports the concern that a change in the law undermines the provision of good palliative care.^{32,33} Consequently, the paradox may be that legislating for some form of active intentional termination of life to promote the autonomy of a minority may well compromise care and choices for the majority. The ethical and clinical perspectives have been well reviewed by Tallis and Saunders.³⁴

2.18 In medicine, the traditional view is that patients with life-limiting diseases should be treated while there is a likelihood that interventions will extend life, the disease burden will be reduced and the patients' suffering or poor quality of life will be improved. Should the patient refuse such treatment, should there be no further significant benefit or should the treatment itself become an unacceptable burden, treatment ought to be withdrawn on the grounds that healthcare professionals should not give treatments they consider to be harmful or futile. With advances in technology that support vital organs (for example, ventilation, ventricular assist devices, implantable defibrillators, artificial nutrition and dialysis), however, circumstances in which biological life becomes explicitly dependent on this technology are increasingly common. The problem is that their withdrawal may lead to rapid death, so that it may become difficult for staff to see their actions as withdrawals from an already prolonged life and not as acts intended specifically to bring about death. Although the philosophy is complex and disputable in the abstract, the pragmatic situation is clear and simple: intending to bring about a death is unacceptable and illegal in healthcare. All people are mortal, however, so life cannot be prolonged indefinitely and a point must come where the right and proper action of the compassionate and caring doctor is to allow a person's underlying fatal disease to proceed and to look after them as they die: although the doctor knows that death therefore may be just around the corner, death itself is not the intended outcome. The guidelines from the General Medical Council (GMC) on withholding and withdrawing life-sustaining treatments is under revision at the time of writing³⁵ and must be made familiar to all clinicians.

2.19 The common law is clear that capable people are the judges of what constitute their own best interests, but means to represent the incapable have remained a problem. Although the Mental Capacity Act 2005 presents challenges in interpretation and implementation, it offers considerable help in managing incapable patients at the end of life. Principally, it:

- ▶ formalises our established duty of care to consult, respect and include patients and, where stated, their advocates in clinical decision making (either donees of legal powers of attorney or court-appointed deputies)
- ▶ updates the test for capacity
- ▶ gives clear instructions on how to construct a view of an incapable patient's best interests
- ▶ offers a framework for capable adults formally to register their wishes, values and decisions in advance should they become incapable. For example, a written and witnessed advanced decision to refuse life-prolonging treatments is legally binding as long as its scope covers the problem in hand and the refusals are specific.

The Department of Justice's own guidelines are encyclopaedic, but digestible guidelines to the act are in preparation by several agencies. The second edition of the National Council for Palliative Care's guidance offers the best advice on aspects of the act that cover the end of life.³⁶

2.20 All clinicians who deal with people who are dying need to have clear understanding of how to discuss, facilitate and make available the proper freedoms and entitlements of their patients and their loved ones and how to engage the distress that comes with incurability and impending death and to have an accurate and clear understanding of the safety of symptom control. Regular collaborative work with specialists in palliative care should be encouraged to review, analyse and audit practice around these difficult ethical cases as a vehicle for support and active learning.

Current demand and future needs

2.21 Surveys of both the general population and those with a terminal illness suggest that most people would prefer to die at home, yet 56% of all deaths from cancer occur in an acute hospital, with only 20% of patients with cancer dying at home in accordance with their wishes.³⁷ The reasons for admission to hospital are complex, including fragile social networks, a wide variety of cultural needs, inexperience in the management of common symptoms, inconsistent community provision, lack of out-of-hours care and ineffective coordination between service providers in addition to acute medical problems. Another factor is the wide range of cultural expectations and practices in relation to death and dying. Community support commonly fails.

2.22 These issues are not going to go away. Trends suggest that in the future people will live longer with cancer and other conditions. Increased social awareness of the management of dying coupled with an ageing population and a reduction in the number of hospital beds mean that the need for palliative care in the community will grow. The challenge is how to meet that inevitable demand.

2.23 The government remains committed to developing care in the community – not just as a response to public demand and wishes but as an appropriate way of delivering healthcare to a population in which most healthcare need and provision should be directed at managing chronic illness. This is being implemented through new models of commissioning and provision that are intended to make services more responsive to local needs. Palliative care lends itself to this approach.

2.24 In the recent report on end-of-life care for London, the data collated on provision and preferences identify seven generic challenges: symptom control, dignity, quality of life, preparation, relationships, coordination and continuity of care, choice and a sense of control.³⁸ Similar themes have emerged from reports of services in other regions. For example, initial findings from the Marie Curie Delivering Choice Project in Leeds, which is designed to improve choices for patients at the end of life, identified that improvements were needed in community support and crisis intervention, education and training, discharge planning and coordination, care for people from ethnic minorities, support for patients and carers, transport, services in care homes and the identification of patients at the end of life. Mechanisms and levers need to be developed and implemented to move health service resources into areas where there is a clear need and where provision can be seen to be more appropriate and cost effective.

SUMMARY

No strategic national plan currently exists for palliative care services. The services are patchy and under-resourced. All patients who are suffering and dying should have equivalent access to palliative care. Palliative care services should be available for the care of patients who are dying of non-malignant conditions. These services must reflect cultural attitudes within society, the differing needs of ethnic groups and the current emphasis on patient choice.

Understanding of the ethical principles that guide palliative care physicians remains poor, and an emphasis on cure with a reluctance to move into the palliative stage of care for the patient is increasing. The attitudes of many healthcare professionals to death and dying, and the attitudes of society as a whole, can exacerbate this problem. Understanding of the positioning of palliative care in patients' journeys needs to be increased.

All clinicians who deal with people who are dying need to have a clear understanding of how to discuss, facilitate and make available the proper freedoms and entitlements of patients and their loved ones and how to engage the distress that comes with incurability and impending death and to have an accurate and working understanding of the safety of symptom control. Regular collaborative work with specialists in palliative care should be encouraged to review, analyse and audit practice around these difficult ethical cases as a vehicle for support and active learning.

Palliative care is the responsibility of all healthcare professionals in primary and secondary care, and training to incorporate the attitudes and principles of palliative care, as well as basic skills, into their practice is needed urgently. This should be supported by high-quality, specialist, multiprofessional teams that cover all care settings.

RECOMMENDATIONS

Palliative care services should accommodate diverse cultures and lifestyles; physical symptoms and the psychological, spiritual and social aspects of care are of equal importance and should be managed appropriately. Development of these services should encompass the current emphasis on patient choice within the framework of the law, and the differing beliefs and needs of ethnic groups must be taken into account.

Referrals are often made late, when patients have multiple problems and significant distress. Clinicians must recognise that end-of-life care does not mean that someone is going to die imminently but that the approach to their care should change. A proactive approach should be adopted to ensure that patients and their families have timely and appropriate care. It is important to identify triggers to ensure that palliative care treatments or referrals are initiated early and appropriately and to use systems of communication that facilitate continuity of care between doctors working in shift patterns.

Clinicians should begin with the general identifier that end-of-life care should start when it would no longer be a surprise if the patient should die in the next year.

All clinicians who deal with people who are dying need to have a clear understanding of how to discuss, facilitate and make available the proper freedoms and entitlements of their patients and their loved ones and how to engage the distress that comes with incurability and impending death.

3 The oncological experience and its application to other diseases

The development of palliative care for patients with cancer

3.1 Before palliative medicine became a specialty in its own right, the management of end-stage malignant disease and the care of patients who were dying were carried out largely by oncologists, other hospital consultants and primary care practitioners. Although these physicians continue to make their own contributions, palliative medicine physicians have been able to take a share in the care of these patients, especially those with complex needs. Collaboration with oncology teams has been crucial to integrating palliative care into mainstream oncology. Other initiatives, such as parallel clinics, have also been successful in building close working relationships. Today, the vast majority of patients seen in palliative care services remain those with a diagnosis of cancer.

Patterns of referral to palliative care

3.2 In patients with cancer, suffering – the principal trigger for initiating palliative care in any patient – may occur at any stage of a disease and is not dependent on prognosis. Cancer has a relatively predictable disease trajectory, which makes triggers for referral to palliative care teams relatively clear cut. In the past, referrals tended to be reactive rather than proactive, being made when no further curative treatment was possible or when patients were clearly in the terminal phase of illness and experiencing multiple problems and distress. Many patients will continue to have active treatment in the last year – and even the last weeks – of life. Society and the medical profession have not caught up with this dilemma, and discussion about the end of life may not occur until active treatment stops, which is much too late for the planning of advanced care. Specialist palliative care needs to recognise the implications of end-of-life management while active treatment is still ongoing; however, tensions may exist between the various professionals with respect to when this stage has been reached.

3.3 Higginson's research on the influence of referral timing on quality of life clearly showed that earlier referral meant less distressing symptoms that were easier to control and better quality deaths.³⁹ A culture that supports earlier referral needs to be developed. Distressing symptoms and complex care needs are the usual reasons, although psychological or spiritual issues have, depending on the model of care available, frequently found their way into palliative care.

Best practice

3.4 Many successful initiatives have improved the care provided for patients with cancer, including the Liverpool Care Pathway, Gold Standards Framework (GSF) and Advance Care Planning. Many of these are easily transferable to patients with a non-malignant diagnosis.

Palliative care for patients with diseases not related to cancer

3.5 Well-structured, coordinated and adequately resourced delivery of healthcare and social care for patients with deteriorating chronic disease is essential. In principle, the model used in patients with cancer could be adapted to suit the needs of patients with non-malignant life-limiting illnesses. This has been achieved successfully within models of good paediatric palliative care, for which cancer is a minority diagnosis. There may be particular difficulties in providing palliative care for patients with non-malignant disease whose local service is predominantly funded or delivered by cancer charities. However, several additional barriers to providing good palliative care in non-cancer settings exist.

3.6 One of these is the uncertain time course of the disease. Lynn and Adamson proposed three models to describe the illness trajectory observed in the common serious chronic diseases (Fig 1).⁴⁰

The first model represents the trajectory associated with patients currently in palliative care – a short period at the end of life in which there is a dramatic decline in overall function (as is seen, for example, in younger people with cancer). The second model represents the trajectory associated with most chronic illnesses – a slow steady decline with intermittent, sharp, reversible declines (as is seen, for example, in patients with chronic heart and lung failure). The third model applies to diseases of old age, sometimes with multiple pathology, in which increasing frailty is the key feature and leads to a slow and protracted deterioration in function until death. This is also seen in patients with chronic neurological diseases, especially in people with dementia.

3.7 A second barrier is patients' and carers' lack of understanding of their disease, their expectations of treatment and their need for involvement in decision making. Together with physicians' lack of training in managing end-stage disease, and further compounded by the dearth of research on non-cancer care, this calls for a new approach. Palliative care should be directed towards the patient's and their family's needs rather than the specific triggers of disease or prognosis. Specific end-of-life care is complex and wide ranging. Another strategy to improve this care is the use of an integrated care pathway (ICP) for people who are dying, as a way of increasing patient focus rather than disease focus in the last few days of life.

Integrated care pathways

3.8 Developed in the United States (USA) in the 1980s, ICPs are an example of a method of implementing best practice and incorporating guidelines into the care of patients with a specific problem. Deviation from the ICP is recorded as a 'variance', and analysis of this enables estimates of quality of care and can promote changes to practice.

3.9 An ICP that was developed in Liverpool for patients who are dying has been adopted by many palliative care teams and implemented in local hospital and community services. The Liverpool Care Pathway (LCP)⁴¹ is intended for use by health professionals outside specialist palliative care services, who are expected to adapt it to local provision and practices after an audit based on 10 goals of care for people who are dying and four goals of care after death. It is appropriate for institutional and home deaths from any cause, as long as they are not sudden or unexpected. As with other ICPs, the LCP includes a document that records adherence to the pathway, simple protocols for the treatment of common clinical problems and triggers for requests for advice or referral. Use of the pathway for an individual patient is triggered by

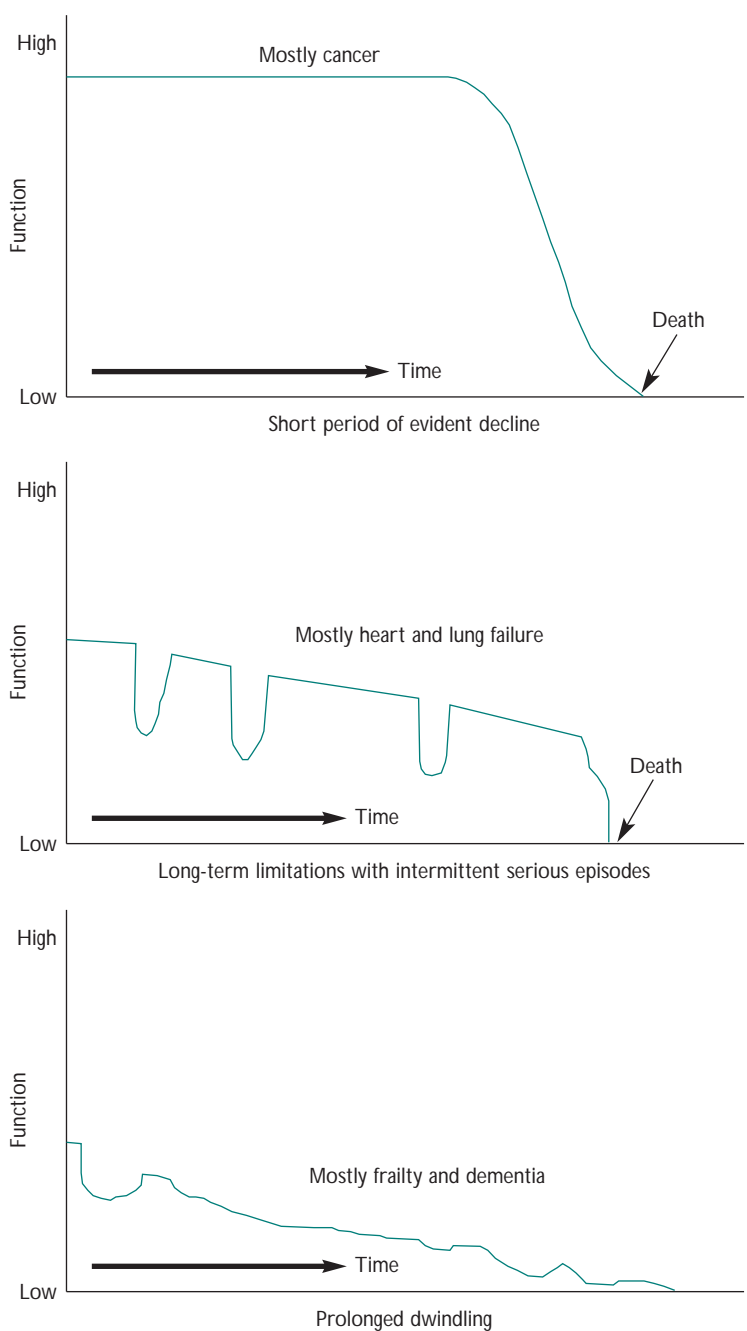


Fig 1. Three models of illness trajectory for serious chronic diseases.

recognition of features that presage death, such as altered consciousness, confinement to bed or difficulty taking oral drugs.⁴²

3.10 The value of the LCP is that it represents a common standard of practice in terminal care for all services, with the expectation that a specialist palliative care hospital support team or home care team will be called in if distress is refractory or loss of control is anticipated. Although the LCP's scope is confined to the last days of life, it complements Advance Care Plans such as the 'Preferred Place of Care' by offering the assurance of a recognised standard in whatever care setting patients choose for their death. The LCP also appears as the seventh and final part of the

GSF,²⁰ which is itself the third element of the Department of Health's End of Life Care Strategy.¹⁹ Evidence and recommendations for some specific diagnoses are given in Appendix 3 to act as exemplars.

Drug treatments: benefits and burdens

3.11 Organ failure at the end of life, whether of the heart, lungs, liver or kidneys, may result in many common symptoms – such as breathlessness, fatigue, weakness, anxiety, depression, anorexia and nausea, as well as pain. Management of these conditions therefore should be directed towards disease-modifying drugs to address the underlying cause as well as drugs and other treatments – for instance, psychological support, physiotherapy or complementary techniques – to palliate the residual symptoms. With multiple pathologies, many different drugs may be needed and patients will be at greater risk of adverse drug reactions and iatrogenic illness. A balance needs to be struck between the potential benefits and burdens of all medical treatments in the palliation of symptoms.

Patients' and carers' perspectives and needs

3.12 The needs of families and other carers require consideration, assessment and appropriate provision in their own right. Their contribution to the support of people with chronic disease who are approaching death is enormous and is often given at great cost – financially, physically and emotionally. Involvement of patients themselves and their families in decisions about the services that they want available to them is needed, together with, where possible, a choice in place of death and bereavement services.

Extending the oncological model to other specialties

3.13 As all people with advancing symptomatic disease and disability should be able to receive good palliative care, its full integration into medical practice is essential. This brings greater responsibility to develop methods for multidisciplinary delivery, communication and support across specialties and between primary and secondary care. The experience with cancer has shown this to be possible. The cancer model forms a good starting point, but the need for more flexibility to address the particular needs of some diagnostic groups is clear. Nevertheless, the similarities in needs among people who are dying far outweigh their differences.

3.14 All clinicians must appreciate the change in emphasis of care once a disease becomes resistant to further treatment. The point at which a disease is recognised as incurable may be difficult to define but is central to good care and best practice for all healthcare professionals. Multidisciplinary delivery of a service requires a common ethos and approach. In the future, palliative care physicians need to work with other specialties through models of shared care and through education to provide subspecialist care (for example, in patients with heart failure, progressive neurological diseases and lung disease).

Older people

3.15 Most deaths in the UK occur in people older than 65 years of age, so this group of people merits special consideration. Although cancer is a common cause of death in the UK, most older people die as a result of cardiovascular, cerebrovascular and chronic lung diseases. Older

people also have an increasing incidence of dementia with increasing age (it affects one in four of those older than 80 years), which creates further difficulties in providing appropriate care (see Chapter 4).

3.16 Older people in their final months are mostly cared for by geriatricians and other specialist physicians in hospitals or by GPs in the community rather than by palliative medicine physicians. Currently, 56% of people in England and Wales die in a hospital setting.¹⁰ Care in the acute hospital setting focuses on the diagnosis and reversal of pathologies; this often results in the continuation of invasive procedures, investigations and treatments, which may be pursued at the expense of the patient's comfort.

3.17 Little information is published on the need for palliative care in older people, who clearly may have quite different needs to younger patients who are dying from cancer. End-of-life care for these patient groups is widely accepted to be far from ideal: older people suffer unnecessarily because of widespread underassessment and undertreatment of their palliative care problems and lack of access to good palliative care. The expertise of palliative medicine physicians needs to be available for the care of older people with multiple pathologies who are dying. The WHO's recent booklets entitled *Better palliative care for older people*⁴³ and *Palliative care – the solid facts*⁴⁴ affirm the importance of this area and encourage the incorporation of knowledge of good generic palliative care into the core curricula of all relevant healthcare professionals, especially doctors, nurses and social workers.

3.18 Dealing with multiple coexisting pathologies, the attendant need for multiple drugs and their potential for harmful drug interactions is a cornerstone of the expertise of geriatricians. Awareness of the need for 'geriatric' expertise among GPs is increasing, while the integration of geriatricians into the medical workforce of secondary care has also brought this expertise into more general medical areas of hospital activity.

3.19 Older patients often have advanced progressive disease from which recovery is not expected, including cancer; cardiac, respiratory, liver and renal failure; and neurodegenerative disease. The term 'end-of-life care' includes the months, or sometimes year, before the death of patients living with advanced irreversible disease rather than just the terminal phase of the final few days. It is essential to be able to identify those older people with advanced disease who may be in their last year of life in order to clarify their needs and priorities and to plan appropriate care. The GSF's *Prognostic indicator guidance*⁴⁵ uses three key questions to help healthcare professionals recognise that the end of life might be close. Such patients therefore can be included in the General Practice Palliative Care Register or Supportive Care Register and their management can be discussed at multidisciplinary meetings.

3.20 When older (as well as younger) patients considered to have reached the last few months or year of life are informed of this, many will want a say in how they are cared for. Communication with patients about their expected prognosis is an essential prerequisite for discussion of their values and choices. Patients may express a preference for their place of care, resuscitation status, proxy and enduring or lasting power of attorney and other specific requests. The GSF recommends that an Advance Care Plan is discussed with the patient and carers. Good communication skills are essential in this sensitive area, and discussion can occur over a period of time. This information should be shared with doctors in secondary care.

3.21 Similarly, the last hours or days of a patient's life must be clearly recognised if the patient is to receive their chosen care – whether in hospital or in the community. On occasion, the diagnosis of dying may be difficult, especially in those with an apparently treatable condition. In this case, a trial of treatment may be warranted in tandem with comfort measures. Failure of response to standard treatments then signals the need for explicit terminal care. Recognition of key signs and symptoms in such patients is an important clinical skill that should be available more widely to non-palliative care staff. Experienced nursing staff are often the first to recognise that an elderly patient is dying, thus emphasising the importance of a multidisciplinary and multiprofessional approach.

3.22 Once a patient is recognised as having only a few hours or days to live, management can be directed primarily towards making them comfortable – both physically and emotionally – as well as communicating this to the patient (where appropriate), family members and friends. Adoption of the LCP is extremely helpful in such a situation.⁴⁶ Use of this pathway has led to improved measurable outcomes of care for patients who are in many hospitals in the UK, as well as in community and care homes.

3.23 Many older people wish to die in their own homes, but few see this wish fulfilled. Where this is possible, the principles and practicalities of good palliative care should enable more to do so, but this also will need GPs and old-age psychiatrists to expand their knowledge base, as well as help from those working in social services.

SUMMARY

Although many patients who die from cancer are cared for by palliative medicine physicians, most people who die in the UK are older people with diagnoses not related to cancer who therefore are not cared for by palliative medicine physicians and who receive a standard of palliative care that is currently extremely variable. People with conditions other than cancer present challenges of care at the end of life. Older people with multiple pathologies highlight the need for greater awareness of the principles and practice of good multidisciplinary palliative care within hospitals and in the community.

RECOMMENDATIONS

When the dying phase is recognised, the use of integrated care pathways for the dying, such as the LCP, should be encouraged for patients with conditions of any disease group not confined to cancer.

A local register should record patients identified as needing palliative care in order to allow planning, review and coordination of services. Information therefore should be available to all general practices and should be disseminated to hospices and secondary and tertiary settings. This will require the appointment of nominated coordinators with administrative and (IT) support and routine connection of all hospices to NHS.net.

Older people who die in hospital should become a priority of care for geriatricians in association with colleagues in palliative medicine. Geriatricians are well placed to use the multidisciplinary approach to provide holistic care to address the multiple symptoms of their patients, whatever their underlying diagnosis. Palliative care should become an important part of the training for geriatric medicine and may need to be given alongside training of specialist palliative medicine physicians.

4 Mental health problems in palliative care

4.1 The issues of mental health are addressed specifically, as many patients who are dying have psychological needs whether the diagnosis is cancer or not related to cancer. In addition, patients with major mental illnesses who develop terminal diseases, and those who die with severe dementia, may experience particular difficulties in accessing palliative care.

Psychological distress

4.2 Psychological distress is common in patients with cancer. The National Institute for Health and Clinical Excellence recommends that: 'should they [patients with cancer] need it, they can expect to be offered optimal symptom control and psychological, social and spiritual support'.¹⁶ Adjustment disorders are the most common psychological reactions to cancer.^{47,48} Despite the negative impact on quality of life and disease outcome, depressive symptoms frequently go undiagnosed and/or untreated.⁴⁹

Specific treatments

4.3 Although antidepressants are used, they may interfere with other physical treatments and are unlikely to resolve complex psychological issues.⁵⁰ Psychological interventions include cognitive skills training,⁵¹ support group interventions,⁵² adjuvant psychological therapy,^{53,54} self-help,⁵⁵ problem solving and relaxation training.⁵⁶ Cognitive behaviour therapy has been evaluated most widely, is preferred by patients and may improve survival in the short term.^{55,57} Complementary treatments, such as aromatherapy, are popular, being used by one third of patients with cancer, although evidence for their efficacy is lacking and their mode of action is poorly understood. In a recent review of supportive treatments for patients with cancer, Newell *et al* concluded that, although the evidence was generally poor, treatments with most promise were group therapy, education, counselling and cognitive behaviour therapy.⁵⁸

Advanced cancer

4.4 Most of the limited evidence available does not relate to patients with advanced cancer – a field in which research is difficult to conduct and requires careful preparation. The impact of psychological distress on the quality of the final months of life and how to improve it thus are poorly understood. Many patients' and carers' groups believe that the balance of priorities in this area needs redress. Defining and recognising anxiety and depression in patients who are receiving palliative care for cancer is complex because of cultural variations in attitudes to death and the overlap with normal reactions to the threat of death. In addition, physical symptoms and behaviours, such as poor sleep and weight loss, are common to patients with terminal cancer, as well as those with anxiety and depression. Although more than 40 studies in the world's literature consider the prevalence of depression in patients with terminal cancer, most were small and had high proportions of non-responders, all were restricted to one community or culture and few provided precise estimates of prevalence.

4.5 The paucity of evidence was highlighted in a recent systematic review of the efficacy of treatments for depression in patients with advanced cancer.⁵⁹ Uncontrolled studies on the efficacy of stimulant (amphetamine analogue) drugs for treatment of depression in advanced cancer are beginning to appear,^{60,61} but much more evidence is needed. Even less is known about anxiety in the late stages of cancer. Evidence suggests that anxiety is common at the time of diagnosis and early treatment, but the use of standardised instruments does not help to differentiate understandable symptoms of anxiety from abnormal anxiety.⁶²

Mental health support for people who are dying

4.6 Towards the end of life, many patients with physical disease develop mental or emotional disorders. Mental health treatments can be provided in a number of ways. Specialist mental health nurses and liaison psychiatrists have roles, and increased training is needed so that existing palliative care staff and professionals in primary care can recognise and manage the more common symptoms and syndromes of psychological decompensation.

4.7 Many people spend the last few days before death at home, within general hospitals or in care homes and may be outside the supportive structure of palliative care services.⁶³ Emergency mental health support in such situations is likely to be drawn from GPs, who may access general psychiatric services, sometimes in response to an urgent call in crisis. Unfortunately, such support is unlikely to be proactive or specially equipped to address the particular needs of the terminal care situation.

Palliative care for people with mental illness

4.8 In the paper *Positive partnerships: palliative care for adults with severe mental health problems*,⁶⁴ the National Council for Hospice and Specialist Palliative Care Services and Scottish Partnership Agency for Palliative and Cancer Care considered the relation between palliative care and mental health services, concluding that needs were not always well met. Specialist palliative care services sometimes feel uneasy and ill equipped to respond to patients with chronic psychosis, active bipolar mood disorder or dementia, yet the same general principles of care should be applied as for any other individuals. The prevalence of delirium in ill elderly people and those who are approaching the ends of their lives is high but often may be amenable to prevention and/or treatment. It is important to differentiate between delirium, dementia and depression (although all three may coexist together). The identification and reduction of predisposing and exacerbating factors, such as visual or hearing impairment, metabolic imbalance and drug interactions, is important.

Palliative care for people with dementia

4.9 Patients who are dying may have dementia alone or in association with other diseases and conditions. Professionals in all settings and across all specialties need to be aware of the complex palliative care needs of this patient group.

4.10 The National Council for Palliative Care's discussion document, *Exploring palliative care for people with dementia*⁶⁵ summarises the complex needs of people with dementia, who tend to be older than those who are dying from cancer and are more likely to spend the last year of their lives in a care home. Unpaid carers deliver most of the care to people with dementia in the UK, and many carers are elderly and frail themselves.

4.11 Our understanding of the palliative care needs of patients with dementia and the natural history of advanced disease is limited. Symptoms progress from memory impairment, which is often complicated by non-cognitive symptoms and behavioural change, with evidence of dyspraxia, dysphasia and agnosia. Physical problems increase with falls, incontinence, difficulty swallowing and inanition. The terminal phase of dementia may include immobility, contractures, decubitus ulcers and recurrent infections, and it may be associated with behaviour that seems to indicate distress and is unresponsive to most approaches to reassurance.

4.12 End-of-life care received by this group is often of low quality. High-quality palliative care needs to be made available to all patients who are dying – not just those with cancer. A recent report on behalf of the Royal Commission highlighted how patients with dementia are unable to access palliative care and, in particular, receive inadequate pain control.⁶⁶ The Regional Study of Care of the Dying found that more patients with dementia experienced pain in the last six months of life than those with cancer.⁶⁷ Carers are rarely informed of the likely outcomes for patients with dementia. Discussions on Advance Care Planning are a means by which carers can plan for the future and feel more supported in making decisions about patient care. Benefits may extend to better resolution of carers' bereavement and reduction in admissions from nursing homes to the acute hospital sector. However, our understanding and clinical recognition of when patients with dementia are entering the terminal phase of illness are poor.

4.13 The provision of care for patients with end-stage dementia presents particular challenges. These include managing complex symptoms – physical and psychiatric – in the face of diminished ability to communicate, dealing with nutritional issues, providing support and advice for carers and families and Advance Care Planning. In addition, dementia has an uncertain trajectory, with onset of the terminal phase being difficult to predict.

4.14 Care of patients with dementia has largely shifted away from the hospital setting into the community; however, as dementia is a progressive disorder, patients often eventually need care in nursing homes. Yet evidence shows that patients with dementia deteriorate when moved and are at greater risk of developing distressing symptoms that may be beyond the experience of the personnel in care homes.

4.15 Some people with dementia die at home or during admission to hospital for other illnesses. Many others survive to die within nursing homes or other long-term care facilities. Evidence shows that the terminal phase of care for people with advanced dementia is less than optimal. Symptoms of distress may remain unresolved, sometimes with no appropriate attempt to ameliorate them. Other patients are admitted repeatedly to acute hospitals for assessment and given ill-informed, inappropriate, life-sustaining treatment that serves only to prolong suffering and add to confusion and distress and that may be associated with the development of additional complications such as decubitus ulcers or colonisation with methicillin-resistant *Staphylococcus aureus* (MRSA).

4.16 Palliative care clearly has a major role in the care of patients with organic brain disease, although many specialist palliative care teams may be unused to dealing with the condition. The reality is that combined services would be unable to cope with the demand – both in terms of patient numbers and high costs of care.

4.17 There is interest in developing hospice-style services for people in the end stages of dementia. Where these have been established in the US, they resulted in improvements in care, and greater confidence and satisfaction among relatives and represented better use of resources.

4.18 Dealing with end-of-life issues is an intrinsic part of mental health practice in elderly people; however, there is currently little cross-specialty training and these issues are not included within the Royal College of Psychiatry's curricula.

SUMMARY

Many patients who are dying struggle with emotional disorders, and patients with mental health problems are particularly vulnerable. Improved liaison with psychiatry and training in the management of mental health problems across community care and for specialist palliative care workers are needed.

Dementia occurs in many patients who are dying from other diseases and conditions, and all professionals in all settings and across all specialties need to be aware of the complex palliative care needs of these patients.

The particular issues that relate to death from advanced dementia have led to the development of specialist hospice-style services in other countries, notably the US. This could be encouraged within the framework of continuing NHS care in the UK.

RECOMMENDATIONS

Professionals in all settings and across all specialties should be aware of and be able to address the palliative care needs of people with dementia and other mental health issues.

Emergency mental health support is essential. This will require the provision of additional training.

5 The organisation of palliative care and workforce provision

Integrated and multidisciplinary care

5.1 Palliative care is multidisciplinary, and many other disciplines contribute to the care of patients and their families. These include medical and nursing staff, social workers, care assistants, dieticians, physiotherapists, occupational therapists, pharmacists, psychologists, counsellors, chaplains, other allied healthcare professionals and administrative and clerical support personnel. Integrated and flexible working across professional boundaries and skill sharing in the team are essential to deliver an adequate service to patients. Within medicine, close cooperation between palliative care specialists, consultants in other disciplines and GPs is mandatory. Provision of high-quality physical, psychological, social and spiritual support is required for patients and their families. The need for improved integration is particularly evident at the healthcare and social care interface.

The Gold Standards Framework

5.2 The development of the GSF²⁰ has gone a long way to enabling primary care services to improve end-of-life care by formalising good holistic practice in a way that is coherent with other general practice routines. Although not taken up by most practices, some of its features appear in the *Quality and outcomes framework* for GPs.⁶⁸ At its heart, is the facilitation of three underlying processes:

- ▶ identification of patients for palliative care
- ▶ assessment of their needs and preferences
- ▶ development of a care plan for the future.

5.3 A programme of support for the primary care team includes information about GSF, education on palliative care, meetings with a GP facilitator and palliative care specialists and resources and advice to set up registers and coordinators.⁶⁹ Seven standards need to be achieved by the primary care team and reported by the lead GP or GSF coordinator according to defined criteria:

- ▶ communication
- ▶ coordination
- ▶ control of symptoms
- ▶ continuity out of hours
- ▶ continuing education
- ▶ carer support
- ▶ care of the dying.

These seven standards are subject to audit and form a basis for evaluating the quality of the delivery of palliative care within a general practice. A version of the GSF based on nursing homes is under development. The GSF is supported by most stakeholders (the Royal College of General Practitioners, NICE, the National Council for Palliative Care and the national service frameworks for renal and heart disease), and in 2003 the Department of Health committed £12 million over three years to help facilitate its implementation (along with two other initiatives – the LCP and Preferred Place of Care).

5.4 The NHS Cancer Services Collaborative and Macmillan Cancer Relief, through its network of GP facilitators, advisors and GSF coordinators, made considerable progress in rolling out the GSF to about one fifth of general practices that have participated in the programme in the UK. The extent to which all the elements of the framework have been implemented by participating practices is variable, but many practices may have taken on some principles of the framework without formal participation in the programme, and this is the subject of current research. Although there are pockets of excellent care, particularly integrated with cancer services, many patients currently slip through the net, and most do not die in a place of their choosing. This is particularly true when the trajectory of illness is not predictable – for example, in those with heart failure or chronic obstructive pulmonary disease and elderly frail people or patients with dementia. This is also true for patients in private sector nursing homes and those from ethnic minorities.⁷⁰

5.5 Although rigorous evidence of the GSF's impact on a large scale is lacking, reports from its early implementation and from qualitative studies of participating professionals were favourable.^{71,72} However, the trend away from practice-based to locality-based community nursing services and the diversity of out-of-hours primary care provision are potential threats to successful continuation of the GSF programme.

Workforce requirements

Medical staff

5.6 Consultants in palliative medicine provide clinical leadership to specialist palliative care teams. They usually work within two or more settings, spanning the acute hospital, hospice and community. Their role includes direct clinical care, leading palliative care MDTs and providing advice to colleagues in primary and secondary care. In many areas, palliative medicine consultants run joint clinics with other specialties and attend site-specific cancer MDT meetings while finding an increasing role in clinical services for cardiac, neurological and renal conditions. Education and training form key elements of the work of most palliative physicians. The limited number of consultants fosters a commitment to improving general palliative care skills in other medical specialties, as well as supervising specialist registrars in palliative medicine. Consultants in palliative medicine frequently play a significant role in the strategic development of palliative care services and also acquire additional responsibilities, such as hospice medical director, clinical lead and clinical tutor, as well as clinical governance and research commitments.

5.7 Palliative medicine became a recognised specialty for training and accreditation in 1987. Until then, hospice services were staffed largely by GPs with a special interest, who maintained part-time general practice. The advent of specialist training led some young doctors to choose palliative medicine as a career, but the piecemeal development of services between the charitable

sector and the NHS has led to a variety of models of medical staffing in different units, with consequent uncertainty in defining a universally accepted standard for staffing levels. The current palliative medicine workforce is inadequate to meet current service needs, and the necessary and significant expansion of specialist services into the management of end-stage non-malignant conditions will exacerbate this problem.

5.8 As the need to care for patients who are dying is generic to all specialties of medicine, generic palliative medicine should be delivered by the medical professional primarily responsible for patients' care. The same principle would apply to diseases such as hypertension or diabetes. Specialist advice should be sought only when the disease becomes difficult to control or its management requires resources only available to the specialist. Provision of generic palliative medicine seems to be patchy among non-specialists, and this situation can be improved only by raising awareness and by education delivered by specialists in palliative medicine.

5.9 Palliative medicine physicians provide direct delivery of complex clinical care to patients and support, education and training to colleagues from a variety of specialties. Significant strategic and management responsibilities are also commonplace. It is not unusual for palliative medicine physicians to be in isolated posts, and difficulties may be compounded for those who work outside the NHS. The wide-ranging responsibilities of a consultant in palliative medicine should be reflected in the individual's job plan.

Consultant staff

Current provision and need

5.10 The RCP's consultant census in 2006 identified 312 consultants in post, of whom 28% are part time.⁷³ This equates to a current whole-time equivalent (WTE) consultant number of approximately 271. A survey in January 2005 revealed 80 unfilled consultant posts.

5.11 The number of WTE consultants needed to manage patients with cancer and non-cancer diagnoses is currently estimated to be one in 160,000 population.⁷⁴ For the UK, therefore, 376 WTE consultants are required (approximately 315 in England, 18 in Wales, 11 in Northern Ireland and 32 in Scotland based on population data for 1 July 2005 from the UK's Office for National Statistics),⁷⁵ but this is a crude estimate that takes no account of local variables and does not allow for future demographic change. If it is assumed that 28% of consultants will work part time in the future, 423 consultants would be needed for the UK (354 in England, 20 in Wales, 12 in Northern Ireland and 36 in Scotland). Continued expansion of the consultant workforce is dependent on the number of trained specialists and the availability of additional funding for posts.

5.12 Currently, there are about 216 specialist registrars (182 with national training numbers (NTNs), six locum appointments for training (LATs) and seven with visiting training numbers (VTNs)), with 19% training flexibly. The average length of full-time training is currently 53 months, as flexible training prolongs the expected four-year programme. With anticipated retirements, this will result in a shortage of new consultants to fill the vacant posts in the short to medium term. Furthermore, this estimate is predicated on the assumption that most non-cancer palliative care will not be undertaken by specialists in palliative medicine. The success of this depends on the education, training and staffing levels in primary care and other specialties.

Related factors

5.13 In total, 63% of palliative medicine consultants are women, with this proportion rising to 83% among specialist trainees. There is, therefore, likely to be an increase in the number of consultants who wish to work part time in future years.

5.14 The RCP's census in 2005⁷⁶ reported that full-time consultants work an average of 43.8 hours per week, with part-time consultants averaging 33.7 hours per week. This is in excess of their contracted hours by an average of 4.2 hours per week. In addition, 22% of palliative care consultants work in excess of 48 hours per week. It is not unusual, particularly in the charitable sector, for consultants who cover inpatient units to provide a 'first-on-call' service with an onerous duty roster. This may be significantly under-remunerated in some cases, as the true cost of out-of-hours medical support may be prohibitive for some small units.

5.15 Much of this time is spent in direct patient care, but the nature of the specialty means that considerable time is spent teaching, training and developing services.

5.16 Consultants in palliative medicine may have responsibilities to lead and develop the service while simultaneously delivering the clinical workload. Integrated care planning frequently is lacking at the hospital-hospice community interface and the NHS-independent sector interface at a local level. Difficulties in strategic planning and operational challenges across healthcare and social care boundaries also are commonplace and exacerbated by poor central strategic planning. The development of local solutions often is led by consultant staff and adds significantly to their workload.

Non-consultant career grade doctors

5.17 Non-consultant career grade (NCCG) doctors have traditionally formed a large part of the palliative medicine workforce. The Association for Palliative Medicine currently has 271 NCCG members, and they accounted for 30% of its membership in 2005.⁷⁷ A questionnaire in 2003 showed that a further 216 NCCG non-members of the association may be working in the specialty (Association for Palliative Medicine, personal communication).⁷⁰

5.18 Respondents to an NCCG survey (2004)⁷⁸ were predominantly women and trained in the UK, with 73% working part time. Just more than 50% considered their role to be similar to that of a consultant, and 44% did not have senior cover on call, with many also being the most senior doctor available during the week. Clearly a sizeable group of NCCG doctors within the specialty have considerable clinical and management experience. Many of these doctors may be dissatisfied with their job titles, roles, support and opportunities for career progression. The survey suggested that 95 would be interested in career progression to consultant and 111 would consider further training to be eligible for the specialist register. This is now possible under Article 14(4) of the Specialist Medical Practice (Education, Training and Qualifications) Order 2003. How many of these doctors will attain specialist registration by this route remains to be seen.

5.19 The possible increase in consultant numbers by conversion of NCCG posts is unlikely to have a positive overall impact on the medical workforce in palliative care. Many would choose to remain as medical directors in their existing units, and others may move to vacant consultant posts, which would leave a gap in service provision at the middle-grade level.

5.20 The nature of specialist palliative care and the workforce shortage means that many doctors – consultants and senior NCCGs – work in isolation. Separation from the NHS in charitably

run units compounds this problem, with, for example, many doctors struggling to identify appraisers and to find cover to enable attendance at activities for CPD. This is clearly a governance issue for small units. Singlehanded posts should be discouraged and local solutions sought. This may mean combining posts across small units or developing solutions based on networks of care.

Other medical staff

5.21 The effectiveness of the current workforce could be enhanced by developing palliative care skills in other personnel. The fourth report of the House of Commons Select Health Committee¹⁰ specifically stated that: 'there are significant challenges in raising the skills of healthcare staff...' Formal training and supervision (see Chapter 6) of GPs with a special interest and medical and surgical consultants could be developed to strengthen their roles in providing generic palliative care to patients and educating other staff in their field of expertise. A logical progression would be to establish a clinical leadership role in each major specialty (for example, renal disease, lower gastrointestinal surgery, etc) to lead on palliative care with the support of consultant specialists in palliative medicine. A similar model could be envisaged in general practice. Closer interaction between specialists in palliative medicine and non-oncological specialties is likely to enhance knowledge on both sides. This would allow, for example, for a cardiologist with a special interest in palliative medicine who could provide clinical advice and education to colleagues on the palliative aspects of cardiology with support from a consultant in palliative medicine. This concept could be developed further into nursing and other allied health professionals' roles. Research is needed into the development of such models of care and their feasibility and effectiveness.

Allied professions and other members of the MDT

5.22 The NHS plan refers to 'breaking down barriers between health and social services'.⁷⁹ Expertise in social work is integral to palliative care management, and close cooperation with the other members of the MDT is essential.

5.23 Although the importance of multidisciplinary teamwork and communication in palliative care is acknowledged widely, investment to achieve this clearly is inadequate. There are shortages of many different professionals in the MDT, including specialist social workers, clinical nurse specialists, palliative care counsellors, psychologists, pharmacists and those who provide administrative support.

Specialist nurses

5.24 This group is of particular importance in medical support, as there is considerable potential for overlap of technical skills and tasks with physicians in both directions. For example, enhanced skills training now allows some nurses to examine and prescribe. In certain circumstances, there is a case for consultant nurses to work alongside general physicians to offer specialist expertise at senior levels. Palliative care nurse specialists are in very short supply around the country, and where they do exist, they are often funded by charities and struggle to fulfil this role alongside other demanding tasks. Great concern surrounds the temporary nature of many existing posts and the heavy dependence on charitable funding (38%).

Current provision

5.25 In 1999, the number of community-based clinical nurse specialists was estimated to be 21 per million population, but with regional variation from 15 per million to 30 per million. Only 16 nurse consultants in palliative care exist in England, and these posts owe less to central planning than to local campaigning. Just as with the distribution of community-based clinical nurse specialists, marked regional variation is seen within England, with central London having four nurse consultants in palliative care but the West Country and north east of England having no such posts. Existing specialist nurses in palliative care fulfil a very important educational and training role.

5.26 A good example of this is in renal services, where the British Kidney Patients Association (BKPA) currently funds the handful of palliative care nurse practitioner and nurse specialist posts that exist around the country. Considering that the average annual mortality for the population who undergo dialysis approaches 25%, and reaches 50% in the elderly and those with other comorbidities such as cardiac disease, there is clearly an enormous unmet need.

Social workers

5.27 Since the advent of care in the community, hospital social workers (now 'care managers') have been involved in assessing inpatients' ability to cope on discharge from hospital and arranging home care where needed. Although care in the community is laudable in theory, in practice it has created many obstacles to the seamless delivery of social care, particularly where the care of people who are dying is concerned.

5.28 Outpatients are no longer the concern of hospital social workers or care managers. Patients are told to contact their local social services for help even if, for example, they have renal failure that requires dialysis three times a week in a hospital setting. In the community, the assessment of need and the development of a care plan may be undertaken by a care manager who does not have the skills and training to be able to carry out a comprehensive assessment of need. Care thus has become fragmented, particularly where the local social services have no specific expertise in the specialist problems of individual patients, and tensions may consequently arise.

5.29 This change in the role of social workers has caused such distress that some specialist units have taken over the funding and organisation of these posts in order to continue to provide appropriate help to all patients. There is a clear need to integrate hospital and community social care and for social workers to work together to deliver the services that individuals need rather than what is neat and convenient and fits the local bureaucracy.

Current provision

5.30 Specialist social workers have particular expertise to bring to MDTs and a valuable role as the patients' advocate, yet huge workforce shortages exist in specialist social work. Macmillan's experience suggests that primary care trusts are more likely to fund specialist and general palliative care services than supportive care. Supportive care services particularly are thus most likely to struggle to find funding. The true cost of social work assessments and advice on benefits for patients who are dying and their carers is estimated to be in excess of £6.8 million.⁸⁰ Statutory funding needs to be provided to address the national shortfall in funding and workforce for these posts. Specialist social workers need to be empowered to arrange community packages of care for their patients directly or to liaise more closely with community colleagues to deliver

seamless care. Some specialties – for example, renal and respiratory – have identified the deficiencies and made recommendations.

Counsellors

5.31 As with specialist social workers, huge variation exists in the availability of counsellors. For patients with renal disease, for example, only 16 identified counselling posts have dedicated renal time in the UK.

RECOMMENDATIONS

Sufficient trained individuals are required to carry out needs assessments for each identified patient and their carers and to generate a comprehensive care plan.

Sufficient appropriately trained staff are needed to deliver the care. Particular difficulties are encountered with out-of-hours care. Interprofessional cooperation and communication must be improved to ensure efficient continuity of care.

The number of WTE consultants needed to manage patients with cancer and non-cancer palliative care is estimated to be one in 160,000 of the population. This equates to 376 WTEs for the UK (344 WTE in England, Wales and Northern Ireland) and is higher than the 271 existing WTE identified in the RCP's census of consultants in 2006. Overall, 83% of specialist trainees are women, and many wish to train part time, which exacerbates the shortfall in new consultants to fill vacant posts and expand the service. A significant expansion of training posts has just been announced for the short term. Expansion of consultant posts is required.

The career aspirations and training needs of the large number of NCCG personnel who work in palliative medicine should be addressed. Personnel at the level of NCCG comprise 30% of the membership of the Association for Palliative Medicine, and many are unhappy with their career opportunities and working environments.

Many consultants are working single handedly in isolated small units. Singlehanded posts should be discouraged, and posts should be shared across small units or formal networks of care established. All palliative medicine clinicians working in charitable hospices should have NHS contracts, with the associated terms and conditions of service, including the need for annual appraisal and access to study leave and CPD.

Statutory funding should be provided to address the national shortfall in funding and workforce for these posts.

Working arrangements between different members of the MDT across primary and secondary care need to be strengthened, with closer liaison between community colleagues and hospital services, particularly out of hours. Specialist social workers should be empowered to arrange community packages of care for their patients directly or to liaise more closely with community colleagues to deliver seamless care.

Significant shortfalls exist for many other healthcare professionals in the MDT. These deficiencies need to be identified by primary care trusts and addressed through commissioning processes.

6 Training

(Recommendations in this chapter are confined to medical practitioners.)

6.1 Large expansion of training posts has been established over the last 12 years, with more than 200 trainees at the end of 2006. An increasingly detailed curriculum has been developed during this period. The current training programme is four years in duration. Entrants to the programme have included junior doctors trained in general medicine (66%) and general practice (33%). The specialty recognises the need to attract more experienced doctors and, therefore, has always been welcoming to colleagues from general practice and other specialties who wish to make a specialty change mid-career. With the advent of the Postgraduate Medical Education and Training Board (PMETB), a revised curriculum is linked to work-based assessments to demonstrate the achievement of relevant competencies. Most palliative medicine consultants act as educational supervisors to specialist trainees, and many are also involved in teaching trainees in other specialties – for example, oncology, geriatrics and general practice.

6.2 Generic palliative care should be a core part of training and a subject for the CPD of all health professionals. This knowledge needs to be maintained and kept up to date.

6.3 Palliative care services are multidisciplinary and interdisciplinary. Education and training for many different groups of healthcare professionals and improved integration and communication across all service providers are needed. The philosophy of care that underpins palliative care should be common to all healthcare professionals and other members of the team, as should an understanding of multidisciplinary practice.

6.4 Doctors in all areas of clinical practice will have responsibility for the management of patients with advanced, progressive, life-threatening diseases of various aetiologies. Palliative care knowledge and skills are prerequisites of good care for these patients. Although it is important to understand that many actively managed illnesses may enter a terminal or palliative phase, it may be very difficult to recognise this transition. Recognition of the palliative phase of illness and its management must be included in medical training at all levels and in all specialties. This must apply to all clinical professions that are responsible for the care of these patients.

6.5 The practice of palliative care requires high-quality teamwork, and the essential components are common to all team members. The essence is excellent communication skills that involve not only interviewing but counselling, listening, leading and following. These skills have to be supported by technical expertise in symptom control and the ability to plan and implement often complex care plans and pathways.

6.6 Teaching of the skills required in palliative care is often delivered by under-resourced specialists in palliative medicine, and this frequently results in conflict between patient care and the role of educator. A specialist in palliative medicine whose role involves delivering training in palliative care should receive recognition of this role in their job plan.

Undergraduate training

6.7 The requirement for education and training is evident, but the curricula at undergraduate and postgraduate levels in medicine are busy, and inevitably there is competition for teaching time. Basic scientific understanding and clinical knowledge are essential, but the ability to make sense of the global issues that attend declining health and recognition of the importance of exposure to the management of all aspects of chronic conditions and people who are dying are equally fundamental for medical education. A national consensus syllabus for undergraduate palliative medicine is now available to guide palliative medicine educators.⁸¹

6.8 An appropriate balance between care and cure must be struck to foster a culture of acceptance of dying, which is somewhat alien in society at large. Undergraduate medical curricula vary in the amount and content of palliative care teaching delivered. Undergraduate education provides the best opportunity to instil future doctors with the principles of good palliative care, which can be developed during postgraduate training. The content, teaching methods and staff undertaking teaching in undergraduate palliative medicine have rapidly developed.⁸²

Postgraduate and specialist training

Foundation training

6.9 Foundation training currently focuses on the management of acutely ill patients, with an emphasis on other generic skills such as communication and therapeutics. More emphasis should be given to decision making for patients nearing the end of life and recognition of the transition from active management of a disease process to palliative care. Basic medical and surgical training should build on these foundation skills, with explicit learning outcomes in curricula that are assessed in practice.

General practice

6.10 General practice requires a high level of palliative care skills. Much decision making around transition points should occur in primary care or with collaborative working between primary and secondary care. Sophisticated forward planning may prevent unnecessary hospital admissions from home or care homes. Communication with patients and families about their choices for end-of-life care often will be led by primary care and must be documented clearly. The use of documentation such as the GSF, Preferred Place of Care, and LCP should be integral to primary care practice, as has been recognised by the Department of Health in the document *Building on the best*.⁸³ Education during general practice training and through CPD and appraisal for GPs is fundamental. This may need to be reinforced by the framework for remuneration for GPs.

Postgraduate specialty training

6.11 Many specialties care for patients with palliative care needs and thus there is widespread need for education and training to deliver generic palliative care. Each medical specialty should address palliative care and implications for that specialty. Each specialty should work with palliative care professionals and lay members to include the following elements:

- ▶ Training issues for junior doctors should be addressed. This would include liaison with respective joint specialist committees and specialty advisory committees. The knowledge and skills needed should be reflected in the competency-based curricula

for each specialty. Reciprocal training with palliative medicine physicians should be considered for specialties with a large palliative care workload.

- ▶ A plan for developing core palliative care knowledge and skills, within CPD, for consultants and NCCG doctors in the specialty should be developed.

6.12 The principles of education and training in palliative care are consistent across medical and surgical specialties, which allows for the development of multidisciplinary teaching. The opportunity to train different specialties together can create synergism by learning from others' experiences. This can be extended to other professional groups for some aspects of palliative care education, especially decision making and communication skills.

6.13 The postgraduate diplomas of the Royal Colleges of Physicians, Surgeons, General Practitioners, Radiologists and Psychiatrists provide the opportunity to ensure that palliative care skills are required for higher specialist training, and the knowledge and skills needed should be reflected in the competency-based curricula for each specialty. Higher specialist training for physicians and surgeons should build on prior knowledge and skills in this area. Curricula should be explicit, and training should be given and assessed. The generic curriculum for higher specialist training in medicine does include some specific learning outcomes in relation to communication and symptom management, but these should be expanded.

6.14 Some medical and surgical specialists manage a large number of patients with palliative care needs. Where this is the case, opportunities for trainees and non-training grade doctors to work alongside palliative care teams should be encouraged. Hospital- and community-based palliative care teams provide a significant amount of opportunistic teaching on the management of individual patients once they have been referred, but resources are stretched. More concentrated experiential learning may be available during special study components for medical students and placements for postgraduate doctors. This is already included in the curricula for higher specialist training in elderly medicine and gynaecological oncology. These are resource intensive, but they should be encouraged for those doctors for whom palliative care will form a large part of their work. The role of clinical leadership in palliative care within medical and surgical specialties could improve this resource issue (see Section 5.21). Specialties for which this could be considered include general practice, chest medicine, cardiology, psychiatry, renal medicine, surgical and non-surgical oncology, acute medicine and neurology.

Continuing professional development

6.15 The importance of ongoing education in palliative care across specialties was recognised by the House of Commons Health Committee's fourth report on palliative care,¹⁰ which urged the royal colleges to 'ensure that training in palliative care becomes part of CPD and to consider making such modules a requirement for revalidation'. Continuing professional development for all doctors must reflect every aspect of their practice over a five-year cycle – not just special interests. The ubiquitous nature of palliative care makes this a relevant issue for all doctors in clinical practice.

6.16 A survey conducted in 2003⁸⁴ questioned all doctors known to the Association for Palliative Medicine on their understanding of appraisal and revalidation and their engagement with CPD. Only 84% of doctors kept any record of their CPD activities, and 55% understood the

requirements for CPD laid down by the RCP. Overall, only 42% of doctors met the minimum requirements of the RCP. Those most compliant were accredited specialists employed within the NHS and the least compliant were NCCGs employed by charitable units. The main problems encountered were time (48%), cover (38%) and funding (19%). Most part-time doctors were doing most CPD in their own time, and many doctors were funding it themselves to a considerable extent.

RECOMMENDATIONS

Palliative care services are interdisciplinary, with care delivered by a MDT. Generic palliative care should be a core part of training for all healthcare professionals, with knowledge and skills maintained and kept up to date.

From foundation training onwards, each medical and surgical specialty should address palliative care provision within the specialty and ensure that specialist curricula and CPD reflect the required knowledge and skills. This must go hand in hand with a clear understanding of the ethics and duties that underpin the change from curative to palliative strategies including the appropriateness of and justifications for withholding or withdrawing treatments and the safety of opioids and sedatives when prescribed competently at the end of life.

The postgraduate diplomas of the Royal Colleges of Physicians, Surgeons, Radiologists and General Practitioners should include specific testing on identified palliative care competencies for each specialty.

Awareness of the requirements for all grades of palliative medicine physicians to undergo CPD and appraisal needs to be raised among managers in the charitable sector. Support must be forthcoming in routine arrangements for cover for absences and financial support.

The role of specialty palliative medicine physicians in the future will include leadership in strategic planning and development of services, support of education and training across a wide range of healthcare professionals and provision of expertise in ethics and clinical decision making, as well as delivery of specialist palliative care to individual patients with complex needs. Workforce planning, CPD and consultant job plans must reflect this.

7 Research

7.1 The relief of suffering at the end of life should be one of medicine's most important goals. In general, research at the end of life across all diagnostic groups is patchy and poor, and much is based on the premise of perceived need rather than objective data. The time course of progression of disability and disease is uncertain and may be confounded by multisystem problems that make end-of-life planning complex and social care and support needs unpredictable. Care, rather than cure, has not been perceived as an academic discipline or amenable to research until recently.

7.2 Little information exists regarding the efficacy and cost effectiveness of the palliative care of patients who are dying of diseases other than cancer. Randomised controlled trials, which are the gold standard of research, are more difficult to undertake in this vulnerable group of people, largely because of uncertain prognosis and professionals' reluctance to burden patients towards the end of life. Evidence suggests, however, that the patients who receive palliative care would welcome more opportunity to participate in research.⁸⁵

7.3 Clinical units tend to be small and independent of NHS organisations capable of sponsoring research. Few centres are capable of coordinating research, and there are few research-active senior academic palliative physicians in the UK. Grant income for clinical studies is limited in comparison with that for other specialties and the non-clinical disciplines associated with palliative care.

7.4 The impact of psychological distress on the quality of the final months of life and how to improve it are poorly understood. Better data on how people die and on their views on dying are also required. The psychological and social needs of different cultural groups also are important and poorly understood.

7.5 Potential research participants constitute a vulnerable group and informed consent may be difficult to obtain because of the effects of disease, drugs or psychological distress. A patient's wishes may be influenced by the views of anxious family members. In addition, uncertain prognosis concerning length of survival, lack of clarity over endpoints and differing attitudes to the ethical aspects of research into end-of-life care add to the difficulties. These issues are addressed in the RCP's *Guidelines on the practice of ethics committees in medical research with human participants*.⁸⁶

7.6 With the emphasis on care closer to home and many patients' wishes to receive care in the community, research is needed into the development of new models of care, including GPs with a Special Interest, as well as the roles of specialist nurses and other allied healthcare professionals. Other models of care need to be studied to determine how palliative care services should integrate with other specialties. This will provide evidence to support the manpower and resource issues associated with an expansion of specialist palliative care practice into non-malignant diseases and primary care. Audits of current practice may highlight potential ways to improve palliative care provision in the community.⁸⁷

7.7 Research into access to care and needs assessment is a priority to ensure equity of provision. Basic and translational research is needed to develop new treatments for patients with symptoms resistant to current regimens. If palliative care is to establish a sound scientific basis for clinical developments in the future, the academic workforce engaged in laboratory as well as clinical studies should be enhanced.

7.8 Lack of commercial drivers for the development of new drugs has led to little change in analgesic regimens since the inception of the WHO's three-step analgesic ladder in 1986. The potential for pharmacogenetic knowledge to help understanding of the wide variety of responses to analgesics and other drugs to control symptoms may never be tapped without a focussed research strategy for palliative medicine.⁸⁸

RECOMMENDATIONS

Research into the efficacy and cost effectiveness of many palliative care interventions is inadequate. Research is needed to determine an evidence base for best practice and to define the most effective elements of current practice. This will require the participation of many NHS clinical units and hospices as well as the facilitation of multicentre clinical studies, including randomised controlled trials.

Better basic research is needed into the techniques of palliative care, the effectiveness of differing treatments, the development of new treatments for symptom control and their acceptability and benefit to patients.

Provision for academic posts in palliative medicine is very limited. This must be rectified in order to progress research and research training in the specialty.

Research into models of care should be conducted to determine how palliative care services should integrate with other specialties to provide care. This will provide evidence to support the manpower and resource issues associated with an expansion of specialist palliative care practice into non-malignant diseases.

National and regional audits of the experiences of patients who are receiving palliative care and the services available to them are needed. Audits should incorporate the care of patients who are dying across a range of medical diagnoses. Information from national comparative audit will lead to improvements in care, in the same way that national audits of the in-hospital care of patients after stroke has resulted in significant improvements in their care.

In order to improve access and equity of provision, research is needed into the development and evaluation of new approaches to the clinical assessment of need for palliative care in the context of uncertain prognosis in a range of diseases and care settings. Identification of clear triggers for referral throughout the course of an illness, where there is evidence of benefit from palliative care services, is important.

The lack of commercial incentives for the development of new pharmacological interventions in palliative medicine is a threat to the exploitation of scientific advances to improve treatment. Enhanced public and voluntary sector funding for translational and clinical research, as well as continued health service research, is needed to alleviate this barrier to progress in the field.

Appendix 1

Witnesses

The Working Party is very grateful to the following people who gave up their time to share experiences and offer advice:

Maggie Bissett

Nurse Consultant, Camden Primary Care Trust

Rodney Burnham

Consultant in Clinical Nutrition, Oldchurch Hospital, Romford

Suzy Croft

Association of Hospice and Specialist Palliative Care Social Workers

Amanda Free

General Practitioner

Irene Higginson

Department of Palliative Care & Policy, King's College London

David Jolley

Faculty of Old Age Psychiatry, Royal College of Psychiatrists

Nigel Leigh

Professor of Clinical Neurology, Penn Hospital, Wolverhampton

Alistair McIntyre

Director, Medical Workforce Unit, Royal College of Physicians

Barbara Monroe

Association of Hospice Managers

David Prail

Chief Executive, Help the Hospices

Mike Richards

National Cancer Director

Vicky Robinson

Consultant Nurse in Palliative Care, St Christopher's Hospice

The Working Party is particularly indebted to Teresa Tate (National Council for Palliative Care) for her written contributions to this report. The Working Party would like to thank Cath Perry, the Working Party Administrator, for her work on the text of the report.

Appendix 2

History of the development of palliative care

Palliative medicine is not new; it has been the style of practice of most physicians from ancient times until the turn of the 20th century, although it was not formalised as a discipline or called 'palliative care' until 1974. Hospices were established in the Roman era, with the word deriving from the Latin for, variously, 'a guest', 'a host' or 'welcome to stranger', with care being provided for travellers, the poor and the hungry, as well as the ill. Interestingly, the Hippocratic school of medicine had eschewed care for the incurably sick or the terminally ill on the basis that this was the province of the gods, while the Aesculapian school took a holistic approach to healing much closer to the philosophy of the modern hospice movement. The traditional hospice movement, which is often associated with religious institutions, continued through the Middle Ages but came to an abrupt end in England with the Reformation. The first hospice solely for people who were dying was opened by Madame Garnier in Lyons in 1842. This was followed by Our Ladies in Dublin in 1879, St Luke's, St Columba's and Trinity in London in the 1880s and 1890s, Calvary in New York in 1899 and St Joseph's in London in 1905. This early identifiable hospice movement had little general impact on care of the dying, although Dr Howard Barrett in his annual review at St Luke's in the 1890s referred to the hospice's philosophy that '...while life shall last we can give peace and rest and much ease from pain...' ⁸⁸ and Snow ⁹⁰ described the use of opiates in the palliative treatment of patients with incurable cancer.

In the first half of the 20th century, inadequacies in the care of people who were dying were well recognised, ⁹¹ but the main impetus for the establishment of formal palliative care services and the hospice movement in the UK today was the 1952 report of the Joint National Cancer Survey Committee of the Marie Curie Memorial Foundation and the Queen's Institute of District Nursing. ⁹² In an interview of 7,000 patients with cancer being cared for at home, high levels of suffering and hardship were found, and the first conclusion of the report was a recommendation for residential homes ('...in addition to providing skilled nursing treatment for the patient, the provision of residential homes would save much mental suffering, stress and strain for the relatives'). A 1960 report by Glyn Hughes found little provision for nursing care for people who were dying, concluded that there was no specific facility for this and recommended that beds should be designated for the terminally ill in new hospital buildings. ⁹³ Hinton described the unsatisfactory hospital care for these patients in poignant detail, concluding that 'the dissatisfied dead cannot noise abroad the negligence they have suffered'. ⁹⁴

It was against this background that the towering figure of the hospice movement, Cicely Saunders, began her pioneering work on palliative care. Her philosophy was first reported in 1958 in an article in the *St Thomas' Hospital Gazette*, in which she wrote: 'it appears that many patients feel deserted by their doctors at the end. Ideally the doctor should remain the centre of a team who work together to relieve where they cannot heal, to keep the patient's own struggle within his compass and to bring hope and consolation to the end.' ⁹⁵

With her background in the humanities, as a nurse, as a hospital almoner and as a doctor, Cicely Saunders was a MDT in her own right and ideally placed to see through parallel developments in palliative care and the modern hospice movement. Her formidable drive and energy and her quiet genius for fundraising led to the establishment of St Christopher's Hospice in South London in July 1967. From the outset, this was to be a facility to provide palliative care but steeped in a discipline of rigorous audit, education, original research and validation of procedures or new developments. The founding principles were based on openness, patient autonomy, a holistic approach, concern for the family, teamwork particularly with specialist nurses, meticulous attention to symptoms and recognition that 'what dying people need most of all is a doctor who will see them as a person: at very least we can stand by them' and that the 'ending of a life can be a final fulfilment of all that has gone before'.⁹⁶ The modern palliative care movement has grown from the St Christopher's initiative, with developments paralleled throughout the world but always strongest in the UK.⁹⁷

Appendix 3

Palliative care and patients who are dying of non-malignant diseases

Cardiac disease

Heart failure is associated with about 60% mortality within five years of diagnosis. It is recognised now as a major and escalating public health problem.⁹⁸ In the UK, around 60,000 deaths a year are attributed to cardiac failure,⁹⁹ and the final months of life for many patients are characterised by chronic and distressing symptoms.¹⁰⁰

The *National service framework for coronary heart disease* identified the need for supportive end-of-life care, finding that 94% of all palliative care services look after an average of only one patient with heart failure and that 10% of services do not undertake any management of patients with heart failure.¹⁰¹ Care may vary from symptom guidance only to a palliative medicine physician coordinating community, hospital and hospice services in a defined geographical area.

Recent research has shown the safe and effective use of opioids in the relief of breathlessness.¹⁰² Palliative medicine physicians can offer their expertise in symptom assessment and drugs in patients whose gastrointestinal absorption is poor, while cardiologists can advise on which drugs for symptom management are least likely to affect cardiac function. Attempts to rationalise drugs remain important, however, as a fine balance exists between the benefits and burdens of taking numerous tablets each day.

The prognosis in patients with heart failure can be considered the least predictable of any chronic disease, with at least half of all patients showing no deterioration in symptoms before death. Specific disease treatment needs to go hand in hand with end-of-life care, with the former predominating in the early phase of the illness and gradually becoming less important in the later stages of the illness's trajectory. Cardiologists, and indeed general physicians who look after these patients, must improve their management of this core aspect of their work for the benefit of patients and to enable palliative medicine physicians to address more specialist cases with complex needs.

Similarly, the development of specialist heart failure nurses who work alongside cardiologists has led to improvement in the care of patients with heart failure in the community, but they have largely felt unable to take on the extra work involved in the palliative care of these patients.

The Working Party heard evidence from Dr Simon Gibbs, a cardiologist, who described a joint study that involved heart failure and palliative care community nurse specialists over a 12-month period. During this time, significant cross-fertilisation not just in technical skill but also in the approach taken to assess the holistic needs of patients with end-stage heart failure was anticipated. Surprisingly, the technical skills transferred easily but not the approach and emphasis of assessment. Clearly, the specialist workforce for heart failure is insufficient for nurses and community palliative care nurses to work side by side, and improved training and shared learning could

improve the service to patients. Palliative medicine physicians have a major role in helping with training needs across the MDT, where the lack of experience in managing end-stage disease may impact on confidence to discuss end-of-life issues. A further barrier to good palliative care may be that patients with non-malignant diseases may have different understanding and expectations to those with terminal cancer.

Respiratory disease

Chronic obstructive pulmonary disease (COPD) is the fifth most common cause of death in England and Wales, accounting for 28,000 deaths each year. In a comprehensive study in the journal *Thorax*, Gore *et al*¹⁰³ showed that none of the patients with COPD studied had been offered specialist palliative care services compared with 52% of patients with lung cancer, despite the fact that there is no difference in symptoms experienced by the two patient groups in the last week of life or over the preceding year.

Chronic obstructive pulmonary disease is the most common chronic respiratory disorder that requires palliation,¹⁰⁴ but other progressive chronic respiratory diseases, such as progressive pulmonary fibrosis or chest wall and neuromuscular conditions, are particularly distressing for patients because of the symptoms of breathlessness, which impinge on all daily activities. These conditions are associated with considerable morbidity and mortality. Like many other non-malignant conditions, the clinical course is difficult to predict – a patient's life can continue for decades, but they may show very rapid deterioration.¹⁰⁴ Recent studies have begun to show the scale of suffering of patients and their families.¹⁰⁵ Patients often have many other distressing symptoms in addition to breathlessness, such as pain, fatigue and low mood, and the prevalence of these symptoms is comparable to that in patients with lung cancer. Patients with severe COPD are often disabled by their disease for longer and have mortality similar to that of many common cancers.¹⁰⁶ Elkington *et al* reported that although shortness of breath and limitation of mobility were the most troublesome symptoms for patients with COPD, only three of 25 patients studied had had access to a specialist respiratory nurse who linked primary and secondary care and was able to give palliative support with a view to minimising symptoms.¹⁰⁷

Although the overall degree of physical and psychosocial hardship is similar between cancer and non-malignant lung disease, patients with end-stage non-malignant respiratory disease are less likely to have received input from palliative care specialists, and formal links with palliative care are variable across the UK.¹⁰⁸ This is partly because of hesitancy from palliative care services: palliative care professionals may be wary of taking on non-cancer patients as skills and experience have developed largely from managing patients with malignancy. There are also concerns about the system being 'flooded' with high demand. Similarly, other healthcare professionals may be wary of referring to palliative care services, perhaps because of difficulties in judging prognosis, professional suspicion over the use of opiates and benzodiazepines in end-stage disease or reluctance to discuss end-of-life issues. Evidence shows that communication about terminal disease is less open with patients with COPD than with patients with cancer.¹⁰⁹

Patients with end-stage pulmonary disease may spend their last few years with increasing disability and dependence on others – for example, family and/or social services – to maintain their activities of daily living. Recurrent infections and repeated hospitalisations are common. Such patients are currently managed in the community by GPs, while general physician teams

manage them in hospital. Recent years have seen the appointment of a number of specialist respiratory nurses who are having a beneficial impact on the care of patients with chronic pulmonary disease in the same way as specialist heart failure nurses. Various studies have identified unmet symptoms and needs in this group of patients, which are similar to those of more typical patients with cancer.

At present, the treatment of all such patients at the point of hospital admission with aggressive medical treatment, which may sometimes include mechanical ventilation, is common practice. In these circumstances, patients may recover from their acute illness but may be left significantly disabled and more dependent after discharge. Others may succumb and be considered as 'failures' of acute treatment. When patients have frequent admissions, they are often treated each time by different medical teams who do not know them from previous admissions. There is no way to predict which patients will respond to such treatment and which will not.

Discussion of the natural history of the disease should be undertaken before the phase of frequent acute deteriorations so that the patient's views and aspirations for end-of-life care can be determined and a more realistic approach can be taken to their future care. A clear decision needs to be made for such patients when the emphasis of care moves towards symptom control rather than just treating exacerbations. Identification of a linked respiratory nurse specialist may help the discussion with patients and their relatives, and it is important that the appropriate respiratory team is taking part in these discussions rather than giving inappropriate aggressive treatment after an emergency admission. The results of these discussions should be recorded in the patient's medical records and conveyed to their GP.

Renal disease

Few studies have considered the provision of palliative care services in patients with end-stage renal failure (ESRF), and there is a need for ongoing research in this area to facilitate evidence-based practice. Most of the existing literature is based in the USA and concentrates on withdrawal from dialysis. Few studies have attempted to evaluate the impact of palliative care services on improving patients' end-of-life care. Despite medical advances, about a quarter of patients with end-stage renal failure die each year and 20% of patients who start dialysis now are older than 75 years and have multiple comorbidities.¹¹⁰ Although the *National service framework for renal disease* specifies that people with renal failure should be allowed to die with dignity in a setting of their choice whether they choose to undergo dialysis or not,¹¹¹ there is currently very little palliative care provision for patients with ESRF.

Geographical variations are seen in the provision of such care, and in a recent survey by Gunda *et al*, only 39% of renal units surveyed had nursing or allied healthcare personnel for whom supportive care was a specified part of their role, and the amount of time spent carrying out this role was negligible.¹¹² It is clear that existing palliative care services in the UK would be swamped if all patients with ESRF who are approaching death were to be referred. The longer course of disease compared with cancer and the less-predictable trajectory (albeit more predictable than many other non-malignant terminal diseases such as chronic heart failure and COPD) make the situation even more difficult.

Nephrologists are increasingly aware of the shift in care provision to working in MDTs and the essential role of the renal unit's social worker in this team. In 2002, the National Renal Workforce

Planning Group recognised that ‘renal social workers care for the needs of patients at the interface of health and social services, addressing the practical, economic, social and psychological problems of patients and carers, helping those with end stage renal disease to cope with chronic disease, disability and eventually death and bereavement’ but identified a shortage of renal unit social workers and a clear shortfall in provision of social services for renal patients in general and patients who are dying in particular.¹¹³ The Renal Special Interest Group of the British Association of Social Workers (BASW) conducted a survey of all renal social work posts in the UK in 2000¹¹³ and identified 54.9 WTE renal social workers, which equates to one WTE per 348 patients who are undergoing dialysis (one WTE per 370 patients who are undergoing dialysis in England). The survey established that 14% of renal units have no specialist renal social work support, 42% of posts are part time and 60% of posts are temporary. The group recommended that one WTE post would be needed per 70 patients who are undergoing dialysis to provide an adequate renal social work service, including counselling and supporting palliative care.

The need to integrate care and enable smooth provision of services is pressing. Currently, pressures within social service departments often lead to fragmented care delivery, particularly when requirements are changing and escalating, as is frequently the case with patients with ESRF who are dying. A vast amount of work needs to be done to meet the comprehensive and laudable standards set out in the national service framework.

Renal physicians, nurses and social workers will need to be trained in palliative care to enable them to provide better end-of-life care for patients, but this is an area in which formal education is limited at present. One particularly difficult area is the control of pain, which Levy *et al* claim nephrologists fail to diagnose¹¹⁴ but occurs in almost 50% of patients with ESRF. Altered drug metabolism in renal failure has meant that many healthcare professionals are reluctant to prescribe analgesics in patients with renal failure.

Another area of concern to nephrologists is that some studies have shown that people from ethnic minority groups, who already have an increased incidence of ESRF, find it more difficult to access palliative care services. People from these groups are likely to be particularly disadvantaged with regard to end-of-life care, with language difficulties and cultural differences producing a challenging environment in which to improve care.

Neurology

The *National service framework for long-term conditions* recommends that palliative care be incorporated into the care of all patients with long-term progressive neurological disorders, such as motor neurone disease and Parkinson’s disease.¹¹⁵ Good evidence suggests that patients want a multidisciplinary approach and to feel that their care is coordinated properly. Primary care should remain the central element in this approach, although home care may not always be possible. The Motor Neurone Disease Association, as an example of good practice, has set up a national framework and created a care standards model.¹¹⁶ Some hospitals have integrated palliative medicine physicians into hospital MDTs to enable a combined approach to care, while community teams – often from the voluntary sector – have negotiated service level agreements with healthcare professionals.

Patients identified as having complex palliative care needs often need additional resources. The need for appropriate practical advice, community and social service support is growing. Some

community teams are able to offer an excellent service, but many patients have to rely on whatever resources local authorities can spare, and there are often financial constraints. The skills and expertise for Advance Care Planning are not widely held.

An excellent network of specialist neurology nurses provide a good standard of care for patients with long-term neurological illnesses. The strength of medical and nursing healthcare professionals' links to palliative care and their levels of palliative care training, however, are variable.

It is important that neurologists or members of their MDTs begin to broach the subject of end-of-life care with their patients. The development of liaison teams, including palliative medicine physicians or nurses, will be helpful in difficult areas, but these should not shoulder the whole workload.

Appropriate training in communication skills is crucial when dealing with difficult end-of-life issues. At present, some healthcare professionals may be fearful of tackling such issues, so patients may be reluctant to raise the subject with their doctors.

Human immunodeficiency virus

Changing epidemiology of human immunodeficiency virus

Since testing for antibodies against human immunodeficiency virus (HIV) became available in the UK, more than 80,000 diagnoses of HIV infection have been made.¹¹⁷ The number of individuals who test positive has increased, with more new diagnoses year on year from 2000 onwards. Since 1999, the number of new diagnoses in which heterosexual sex is the presumptive cause of transmission has outnumbered those with homosexual sex as the presumptive cause.

Of increasing concern are surveillance findings that rates of primary HIV resistance in the UK – ie new infections with viruses that have reduced responses to currently available anti-HIV drugs – have been among the highest reported and, more recently, seem to be increasing with time.¹¹⁸

As a result of increased numbers of newly diagnosed infections and reduced mortality, the total population within the UK that is infected with HIV continues to increase. Estimates from 2006 suggest that 63,500 people are infected with HIV, with 20,100 of these currently unaware of their infection.¹¹⁷ Many of these people may be diagnosed 'late' in their illness and may be more likely to require palliation.

Highly active antiretroviral therapy (HAART) resulted in one of the most significant medical advances in terms of changing the outcome of any medical condition in recent times, with the number of deaths dropping considerably between 1995 and 1997 in the UK but remaining relatively constant since then. The incidence of almost all opportunistic infections has decreased,¹¹⁹ withdrawal of prophylaxis has been successful¹²⁰ and AIDS-associated tumours – predominantly Kaposi's sarcoma and non-Hodgkin's lymphoma – are less common.^{121,122} Significant mortality, however, remains associated with these conditions, which thus need palliation.

Opportunistic infections and tumours continue to occur in those who refuse or are unable to tolerate HAART.¹²³ Furthermore, HAART is an imperfect treatment: toxicity, complications, complex treatment regimens and viral resistance mean that a significant minority of patients will remain increasingly prone to disease progression. A significant role for palliative care is to assist the HIV clinician in managing side effects. This is likely to improve treatment adherence.

Given the common transmission routes of HIV, hepatitis B virus (HBV) and hepatitis C virus (HCV), a significant proportion of individuals will be coinfecting. Accelerated progression of HBV¹²⁴ and HCV¹²⁵ is associated with poorer response to treatment of each hepatitis virus infection; in addition, coinfection is associated with poorer tolerance of HAART and possibly poorer response to treatment for HIV. Unsurprisingly, therefore, liver-related mortality is reported to be increasing in these patient groups.¹²⁶ Although not recognised as ‘AIDS defining’, patients infected with HIV generally have increased susceptibility to a number of other tumours that are increasingly recognised as associated with HIV, including tumours of the lung, testis, colon, skin and anus.^{127,128}

Neurological dysfunction is a further potential significant long-term issue. Irreversible neurological deficits may occur secondary to HIV infection per se (eg HIV encephalopathy/AIDS dementia complex or HIV myelopathy) or opportunistic infection, and immune reconstitution may prevent worsening of functioning but not result in an improvement. In such individuals, long-term palliation may be required in the absence of progressive immunosuppression.

Changing patterns of service provision

The development of models of HIV care in the early days of the HIV epidemic was characterised by multidisciplinary working (including cooperation between ‘HIV providers’ and ‘palliative care providers’), and this frequently is used as an example of good practice to other areas of medicine.

A major shift has occurred since the development of effective anti-HIV treatment, with HIV service providers increasingly becoming experts in antiretroviral treatment. Training and experience in more holistic aspects of patient management – including palliation – have become less significant as the management of HIV has become more medicalised.¹²⁹ Conversely, palliative care physicians have become decreasingly involved in the management of patients with HIV as the model of care has shifted to one of a chronic manageable disease rather than an acute terminal process.¹³⁰ Disinvestment in palliative care services associated with HIV has occurred as a result of increasing demands on NHS services overall and a shift in the emphasis within HIV care towards funding of HAART.

This has occurred despite major uncertainty in prognosis, unmet need and barriers to access in the UK for palliative care input to the management of HIV.¹³¹ Although a recent review of the evidence for a benefit of palliative care input has demonstrated a lack of robust evidence,¹³² studies in the post-HAART era have continued to show that HIV clinicians underestimate a need for palliative care input despite a high prevalence of symptoms that would benefit from it.¹³³ This supports the assertion that a ‘false dichotomy’¹²⁹ remains between curative and palliative care in the field of HIV.

Considerations for palliative care

The number of individuals living with HIV in the UK is likely to continue to increase inexorably. Although massive advances in the treatment of HIV have been made, significant morbidity and mortality in people with HIV will continue due to:

- ▶ late diagnosis or infection with drug-resistant HIV
- ▶ treatment failure or refusal and HAART-associated toxicities

- ▶ complications of HIV that may be resistant to treatment
- ▶ comorbidities (e.g. hepatitis coinfection) and other malignancies (e.g. anal carcinoma)
- ▶ HAART-resistant neurological disease.

When input from palliative care clinicians is needed, it should acknowledge specific factors that affect those infected with HIV, including psychosocial and legal issues, as well as medical problems. Training of HIV clinicians needs to maintain a palliative care component, and, conversely, training in palliative care needs to include some awareness of the specific issues pertinent to HIV. Services for patients with HIV require direct access to and close liaison with palliative care services.¹³⁴ Research is needed to determine the requirements for palliation in patients infected with HIV and the optimal model for holistic management in the post-HAART era in the UK.

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