



Royal College
of Physicians



NHS

National End of Life
Care Programme

Improving end-of-life care: professional development for physicians

Report of a working party

March 2012

Acknowledgements

We would like to thank Jo Horsborough (educationalist, Royal College of Physicians, London) and Claire Henry (director of the National End of Life Care Programme) for their support in preparing this report.

The Royal College of Physicians

The Royal College of Physicians is a registered charity that aims to ensure high-quality care for patients by promoting the highest standards of medical practice. It provides and sets standards in clinical practice and education and training, conducts assessments and examinations, quality assures external audit programmes, supports doctors in their practice of medicine, and advises the government, public and the profession on healthcare issues.

Citation for this document

Royal College of Physicians, National End of Life Care Programme, Association for Palliative Medicine of Great Britain and Ireland. *Improving end-of-life care: professional development for physicians*. Report of a working party. London: RCP, 2012.

Copyright

All rights reserved. No part of this publication may be reproduced in any form (including photocopying or storing it in any medium by electronic means and whether or not transiently or incidentally to some other use of this publication) without the written permission of the copyright owner. Applications for the copyright owner's written permission to reproduce any part of this publication should be addressed to the publisher.

© Royal College of Physicians 2012

ISBN 978-1-86016-474-3
eISBN 978-1-86016-475-0

Review date: 2015

Royal College of Physicians

11 St Andrews Place
Regent's Park
London NW1 4LE

www.rcplondon.ac.uk

Registered Charity No 210508

National End of Life Care Programme

3rd Floor, St John's House
East Street
Leicester LE1 6NB

www.endoflifecareforadults.nhs.uk

Association for Palliative Medicine of Great Britain and Ireland

76 Botley Road
Park Gate
Southampton SO31 1BA
www.apmonline.org

Typeset by Dan-Set Graphics, Telford, Shropshire

Contents

Members of the working party	iv
Foreword	v
Statement of endorsement	vi
Executive summary and recommendations	vii
1 Introduction	1
2 Methodology and remit	3
Working party remit	4
3 Issues clinicians face in delivering high-quality end-of-life care	5
4 Educational approaches to professional development in end-of-life care	7
Strengthening multidisciplinary and multiprofessional teams	7
Developing communication skills	7
Learning from clinical practice	7
Learning from patients and carers	7
Developing competence and confidence	8
Disseminating innovations and effective practice	8
Promoting cultural change in organisations	8
5 The need for and provision of CPD across the UK	9
6 Evidence gathered from physicians	12
Survey	12
Telephone interviews	17
Focus group discussions	18
References	22
Appendix 1 Top ten tips for physicians	24
Appendix 2 Prompt tool for post-take ward rounds / general ward rounds	25
Appendix 3 Prompt tool for mortality and morbidity meetings	26

Members of the working party

Fiona Hicks (chair)

Consultant in palliative medicine, Leeds Teaching Hospitals Trust; senior clinical lead for end-of-life care, Yorkshire and the Humber SHA

Richard Berman

Consultant in palliative medicine/honorary senior lecturer, Christie NHS Foundation Trust, Manchester

Sarah Cox

Consultant in palliative medicine, Chelsea and Westminster NHS Foundation Trust and Trinity Hospice; honorary senior lecturer, Imperial College Medical School

Stephanie Gomm

Consultant in palliative medicine, Salford Royal NHS Foundation Trust; chair, Joint Specialty Committee for Palliative Medicine, Royal College of Physicians and Association for Palliative Medicine of Great Britain and Ireland

Jackie Morris

Consultant physician, British Geriatrics Society dignity champion; honorary research associate, Institute of Epidemiology and Health, University College London Medical School; honorary senior fellow, City University, London

Katy Newell-Jones

Consultant in learning and teaching; national teaching fellow, Higher Education Academy, York

Teresa Tate

Consultant in palliative medicine, Barts and the London NHS Trust; deputy national clinical director for end of life care, Department of Health; medical adviser, Marie Curie Cancer Care

Bee Wee

Consultant in palliative medicine, Sir Michael Sobell House, Oxford Radcliffe Hospitals NHS Trust; president, Association for Palliative Medicine of Great Britain and Ireland

Conflicts of interest: none.

Foreword

Well over a quarter of a million people die in hospitals in England each year. This is more than the combined total for deaths at home, in care homes and in hospices. In an average-sized NHS trust, four or five patients are likely to die every day, and the number dying can be twice this in a large trust. However, we know that end-of-life care in hospitals often falls short of the standard we would wish for ourselves, our relatives and our friends.

We welcome the practical recommendations set out in this report. They are based on the results of a survey of more than 1,800 physicians and in-depth interviews and focus groups. Although clinicians rated their confidence in discussing end-of-life care with those approaching the end of their lives highly, two thirds reported that they had not attended any professional development event on end-of-life care in the last five years. Ratings of support for education on end-of-life care from trusts and organisations were also generally low. In contrast, experiential learning from working alongside palliative care teams was identified as an important source of learning.

Improving the quality of end-of-life care in hospitals is a very high priority in the End of Life Care Strategy published by the Department of Health. Implementation of the recommendations from this working party will do a great deal to make this a reality.

Professor Sir Mike Richards

*National clinical director for cancer
and end of life care*

Professor Dame Sally C Davies

Chief medical officer and chief scientific adviser

Professor Sir Richard Thompson

President, Royal College of Physicians

Statement of endorsement

This document rightly highlights that most physicians will be involved in the provision of end-of-life care during their careers and that they need particular skills to meet the challenges that this can present.

As the report notes, these skills should not be the sole preserve of end-of-life care or palliative care specialists. In setting out proposals, there is a clear call for improving pre- and post-registration training and education in end-of-life care for physicians. This report recognises the importance of issues such as patient choice, closer working between primary and secondary care, and multidisciplinary working. We strongly endorse that approach and the recognition of the place of e-learning, for example the free e-learning resource, e-ELCA (www.e-elca.org.uk), which offers around 150 learning sessions on end-of-life care.

The working party has laid out a clear path for helping consultants and their teams to improve end-of-life care. We urge the relevant training and regulatory bodies and employers to start down that path with little delay.

Claire Henry
Director, National End of Life Care Programme

Executive summary and recommendations

There is broad recognition that the delivery of good care at the end of life cannot be left to specialists in palliative care but is an important part of the role of most physicians.

As the population of the UK ages, the death rate will rise steadily from 2012, mostly among the very old. The oldest old are likely to die after a period of increasing frailty and many will also suffer from dementia.

Recognition that someone is entering the last phase of their life is pivotal to establishing patient priorities for treatment and care and to balancing therapeutic burdens and benefits. Doctors may fear charges of therapeutic nihilism or futile overtreatment.

End-of-life care marks the last phase of life, which may span many months or even years. Late recognition of deteriorating health, and a prevailing culture where this is not openly discussed with patients until the last days of life, leads to most people dying in the acute hospital environment. When asked, most people would prefer both to spend more time, and to die, at home.

The first national End of Life Care Strategy for England, published in 2008,^{A1} and its counterparts in Scotland and Wales encouraged early recognition of people entering the last phase of their lives with open, sensitive discussion of their preferences for type and place of care. It emphasised that this must be underpinned by training and professional development for a range of staff who deliver care at the end of life.

Many people will continue to die in the acute hospital environment, either by choice or because of the circumstances of their illness. Delivering high-quality care to the dying remains a key part of hospital practice.

Effective education should start at undergraduate level and continue through postgraduate training.

Hospital trusts and their commissioners have a responsibility to see the delivery of high-quality end-of-life care as part of their core work and to support a learning culture, encouraging professional development for staff at all levels. This should be underpinned by their clinical governance systems.

In recent years a wealth of resources has been developed to support the delivery of high-quality care within and across care settings. Although some, such as the Liverpool Care Pathway for the Dying Patient (LCP),^{A2} have been widely adopted, most have not yet become part of routine practice at a personal or organisational level.

In developing this report, the working party conducted an online survey of nearly 2,000 physicians, which was followed by focus groups and telephone interviews. Most physicians recognised the importance of delivering good end-of-life care in their practice. The majority reported that they were confident and competent in most aspects of such care, although less so when dealing with advance care planning and people with dementia. Surprisingly, only a third had attended any learning event on end-of-life care in the last five years and many of the events were about communication skills.

Data from complaints and audits would suggest that the self-reported confidence of physicians is sometimes misplaced or that physicians are not putting their skills into practice. The earlier identification of patients entering their last phase of life and planning with them for their preferences for care is an area that is particularly lacking. Patients and their carers have an important role in helping staff to consider their practice more carefully. Patient stories provide a powerful resource, although, in this context, they may be told by bereaved carers. Physicians should seek ways to incorporate patients' feedback into their day-to-day care.

Continuing professional development is best integrated into routine clinical practice. This delivers the most powerful learning and reduces the need for staff to leave practice to attend more formal learning events. E-learning is a useful way of supporting learning in practice; it is widely available and its use should be encouraged.

Hospital palliative care teams have a key role in setting the culture for end-of-life care, as well as in delivering high-quality care to those with the highest level of need. Physicians reported having learnt most from spending time with good palliative care teams and services in joint clinics, ward rounds or placements.

Specialists in palliative care should look to deliver more local teaching and be open to staff requesting joint working. They should be prepared to work with physicians in all relevant specialties and learn from them about the issues faced by different patient groups, as well as sharing their own knowledge and expertise. This type of work-based learning is time intensive and palliative care teams should be resourced to make this possible.

The use of an integrated care pathway for the dying, such as the LCP,^{A2} has helped physicians to deliver high-quality care in the last hours and days of life, when it has been underpinned by an extensive programme of education and support. The introduction of tools without such support may lead to a 'tick-box' approach, which is counterproductive and should be discouraged.

Tools to help physicians recognise the last phase of life earlier in patients' illnesses and to begin to talk with them about their preferences, such as the AMBER care bundle,^{A3} should be developed and evaluated. Such tools should be introduced with due regard for the training and support needed to use them appropriately and sensitively.

End-of-life care should be incorporated into established learning events as part of study days run by colleges, specialist societies and networks on long-term conditions, extending the reach to those who would not self-select for end-of-life professional development. Physicians would value more local events, although they are unlikely to attend full-day events just about end-of-life care. Joint learning with GP colleagues can help to bridge the gap between primary and secondary care.

To support the earlier identification of patients nearing the end of their lives and to encourage sensitive discussions about their preferences, we have developed prompt sheets that can be incorporated into day-to-day hospital practice.

Recommendations

These recommendations have been grouped under subheadings to highlight where the main responsibility for their implementation lies. The chapter from which each recommendation derives has been included in brackets for ease of reference.

Recommendations for trust boards

- ▶ Trust boards should make the delivery of high-quality care at the end of life a priority for their organisations. End-of-life care metrics should be developed, based on the End of Life Care Strategy^{A1} quality markers for acute hospitals, and should be included on their management dashboards and risk registers (Chapter 1).

- ▶ Senior management support is critical to enable professional development in end-of-life care. This must include:
 - provision of time for learning
 - appropriate appraisal systems that encourage continuing professional development in end-of-life care
 - an organisational culture that values quality of care at the end of life (Chapter 3).
- ▶ Hospital trusts should review the provision of learning opportunities for their consultant, trainee and non-training grade workforce and, where necessary, increase the availability of local end-of-life care training and education (Chapter 6).
- ▶ Tools such as care pathways for end-of-life care must be properly implemented and should receive continuing support to sustain the learning that is required, otherwise such tools can be counterproductive by encouraging a ‘tick-box’ approach rather than promoting high-quality care (Chapter 6).
- ▶ The introduction of systems of care that help to highlight patients who may be at risk of dying during a hospital admission, such as the AMBER care bundle^{A3} or equivalent, should be considered as a tool to help professional development within teams and to guide day-to-day practice (Chapter 6).

Recommendations for commissioners

- ▶ Commissioners and hospital trusts should consider how they can support the uptake of training in end-of-life care – for example, by using the Commissioning for Quality and Innovation (CQUIN) framework.^{A4} Example standards should be based on the End of Life Care Strategy quality markers and might include specifying a proportion of physicians conducting a patient/carer survey of experience under their care, team-based learning events around death reviews and a percentage for educational uptake in a target proportion of medical staff (Chapter 1).
- ▶ The role of hospices and specialist palliative care units/teams in providing experiential placements for physicians should be recognised and resourced (Chapter 6).
- ▶ Training in advanced communication skills for physicians who care for those with long-term conditions should have equal priority and resources as the training required for those involved in caring for patients with cancer (Chapter 5).
- ▶ Hospital palliative care teams should be available in each hospital and should be resourced to lead the delivery of professional development in end-of-life care. As experiential learning is most valued, this should include time to work with colleagues in clinical practice and to provide clinical placements and mentorship (Chapter 6).

Recommendations for physicians

- ▶ Physicians whose practice includes patients in the last phase of their lives should consider using the ‘Top ten tips’ and ‘Prompts for ward rounds and mortality and morbidity meetings’ provided in this report during their routine practice (Chapter 6).
- ▶ Medical consultants should provide leadership in establishing opportunities for professional development in end-of-life care in their own settings, including agreeing how best to implement this as a department/directorate and across the trust (Chapter 3).

- ▶ Teams involved in end-of-life care should actively plan for cultural change in the delivery of care at the end of life by identifying medical leaders, engaging colleagues and supporting the development of expertise among colleagues (Chapter 4).
- ▶ In order to influence their practice and ensure that patients have time to adjust, physicians must recognise that end-of-life care is not just care in the last few hours and days but that it marks the last phase of life, which may be many months or sometimes years (Chapter 3).
- ▶ Professional development for end-of-life care should:
 - strengthen multiprofessional teams and promote collaboration between team members
 - support the development of effective communication skills through interactive approaches such as simulation, observation and practice with feedback
 - use opportunities in routine practice to draw on clinical experiences with a direct relevance to patient care, developing problem-solving and reflective skills
 - actively seek engagement with, and feedback from, patients and caregivers to improve understanding of the patient experience
 - be embedded into a wide range of educational events such as conferences, workshops and study days, not just those that focus specifically on end-of-life care (Chapter 4).
- ▶ Reflection and learning on end-of-life care should be integrated with daily clinical practice. This may be done through directorate meetings; structured multidisciplinary meetings; mortality and morbidity meetings; joint ward rounds and outpatient clinics with palliative care colleagues; grand rounds; mentoring; and placements (Chapter 6).
- ▶ Consultants who provide care at the end of life should incorporate this into their continuing professional development (CPD) and undertake at least one learning event in end-of-life care within a five-year CPD cycle. This should be reviewed at their annual consultant appraisal (Chapter 6).
- ▶ Hospital and primary care teams should acquaint themselves with the range of general and disease-specific tools to identify patients with advanced illness, or who may be approaching the end of life, and consider their applicability and use within their routine practice (Chapter 6).
- ▶ Joint learning with GPs should be encouraged to further the understanding of each other's roles and services and to improve coordination of care across traditional boundaries (Chapter 6).
- ▶ The use of e-learning, such as End of Life Care for All (e-ELCA),^{A5} to support work-based learning should be included where relevant (Chapter 6).

Recommendations for palliative care teams

- ▶ Specialist palliative care clinicians should develop wide-ranging educational skills in supporting colleagues through formal and non-formal learning by:
 - using structured interactive events
 - facilitating effective bedside teaching
 - conducting joint ward rounds and mentoring colleagues
 - facilitating mortality and morbidity meetings (Chapter 4).
- ▶ Hospital palliative care teams should include leading professional development in end-of-life care as an integral part of their role. This should include providing support as well as working with staff from other disciplines and professions to learn with, and from, them (Chapter 6).

- ▶ Local palliative care providers should work with the palliative and end-of-life care networks to deliver more extensive and targeted CPD for physicians (Chapter 5).

Recommendations for medical schools and foundation programmes

- ▶ All medical schools in the UK should review their undergraduate curricula to ensure that they provide an adequate grounding in end-of-life care, as outlined in *Tomorrow's doctors*^{A6} (Chapter 1).
- ▶ All foundation schools should review their delivery of the foundation curriculum in relation to end-of-life care (Chapter 1).

Recommendations for the Royal Colleges of Physicians

- ▶ The chairs of each specialty advisory committee should review their training curricula in regard to end-of-life care in the light of this report (Chapter 1).
- ▶ The Royal College of Physicians and specialist societies should promote the inclusion of end-of-life care within study days and conferences related to long-term conditions (Chapter 5).

References

- A1 Department of Health. *End of life care strategy: Promoting high quality care for all adults at the end of life*. London: DH, 2008. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
- A2 Marie Curie Palliative Care Institute. Liverpool Care Pathway for the Dying Patient. www.lcp.mcpcil.org.uk/liverpool-care-pathway
- A3 Modernisation Initiative: end of life care. *Innovative practice. The AMBER care bundle*. 2010. www.tin.nhs.uk/EasySiteWeb/getresource.axd?AssetID=37208&type=full&servicetype=Attachment
- A4 NHS Institute for Innovation and Improvement. Commissioning for Quality and Innovation (CQUIN) framework. www.institute.nhs.uk/world_class_commissioning/pct_portal/cquin.html
- A5 e-Learning for Healthcare, Association for Palliative Medicine of Great Britain and Ireland. *End of life care for all* (e-ELCA). An e-learning project. www.e-elca.org.uk
- A6 General Medical Council. *Tomorrow's doctors: outcomes and standards for undergraduate medical education*. London: GMC, 2009. www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp

1 Introduction

'Knowing is not enough: we must apply. Being willing is not enough, we must do.'

Leonardo Da Vinci

Since the publication in 2007 of the Royal College of Physicians (RCP)'s working party report, *Palliative care services: meeting the needs of patients*,¹ there has been a growing impetus for palliative care and end-of-life care to be accessible to all those in need, whatever their underlying disease. In 2008, the NHS bodies in England, Scotland and Wales published strategies for end-of-life care,²⁻⁴ which provided frameworks for improving end-of-life care across all settings. Each put a strong emphasis on the need for education, training and continuing professional development (CPD) at all levels. The National Audit Office (NAO)'s report, published later the same year, supported the strategies.⁵ In particular, the NAO's report noted that there were 'significant gaps in the education and training curricula' for health professionals and recommended that the General Medical Council (GMC) address the issue of raising awareness of and improving skills involved in identifying and delivering end-of-life care. In addition, end-of-life care is one of the eight national Quality, Innovation, Productivity and Prevention (QIPP) workstreams set up as a result of the *NHS next stage review* led by Lord Darzi, which was also published in 2008 (Department of Health).

Around 1% of the population dies each year, which amounts to about 500,000 people in England. Of those, 58% die in hospital, largely under the care of physicians,⁶ and up to 75% of deaths are considered to be 'expected'.⁷ The death rate in the UK has been falling, but it will start to increase from 2012 as the population ages.⁸ Death largely occurs in old age, with two-thirds of deaths in 2008 occurring in people aged over 75. Overall, the largest number of deaths was in people aged 80–89, who accounted for more than one third of deaths. In 2008, 17.1% of all deaths were of people aged 90 and over. As the population has aged, the prevalence of dementia has increased, and this is now one of the 10 most common causes of death in women aged 70–79. The proportion of deaths from pneumonia is also higher with increasing age, representing 3.6% of deaths in men and 4.3% in women aged 75–79 years, and 12.1% in men and 11.7% in women aged 90 years and over.⁹ These changes illustrate the importance of ensuring that physicians are well trained and supported to deliver high-quality end-of-life care, particularly to older patients with non-cancer diagnoses, often in the context of underlying dementia.

The importance of professional development in end-of-life care has been highlighted in a number of recent publications:

- In 2009, the Department of Health published a set of quality markers to support the End of Life Care Strategy.¹⁰ One of its top 10 markers relates specifically to the accessibility of training opportunities in end-of-life care.
- The GMC's guidance on treatment and care towards the end of life came into effect in July 2010.¹¹ This included specific expectations that doctors participate in 'educational activities that maintain and develop your competence and performance' in the care of patients towards the end of life.
- The RCP has made end-of-life care a priority, reviewing specific competencies embedded in training curricula for core medical and specialty training and including it as one of the five key themes in the publication *Leading for quality: the foundation for healthcare over the next decade*.¹²

Since 2008 there has been a step change in the education and training opportunities offered to a wide range of doctors. At the undergraduate level, the Association for Palliative Medicine of Great Britain and Ireland (APM) has endorsed a consensus syllabus for undergraduate palliative medicine¹³ that builds on the GMC's syllabus in *Tomorrow's doctors*.¹⁴ The National End of Life Care Programme has published a wealth of

documents for qualified doctors, including the 'Routes to success' series, which highlights how end-of-life care can be improved in a variety of settings.¹⁵ In recognition that skilled communication underpins much of the delivery of good end-of-life care, the Department of Health (DH) funded a series of pilot trials of different approaches to training in communication skills,¹⁶ which has resulted in the publication of recommendations and resources to support practice. In addition, the DH has funded eight pilot trials across England to develop and use electronic palliative care coordination systems (EPCCS) in order to encourage staff to identify patients nearing the end of their lives and to improve communication between services about their care.¹⁷

Several documents have been produced to highlight and encourage good practice in certain specialties and disease groups.^{18–20}

In addition to traditional methods of classroom and bedside learning, there have been considerable developments using online media. e-Learning for Healthcare has supported the development of more than 150 e-learning sessions in end-of-life care in conjunction with the APM,²¹ and a module in palliative care within the e-GP programme in conjunction with the Royal College of General Practitioners.

Support for professional development in end-of-life care has also come from the 10 strategic health authorities (SHAs) in England, which have used funding from their multiprofessional education and training (MPET) budgets to target this specific area of practice. The nature and extent of this has varied between SHAs, and different systems apply in the other countries of the UK. However, our own survey suggests that nearly 30% of training accessed by physicians was on communication skills.

In November 2011, the National Institute for Health and Clinical Excellence (NICE) published a quality standard on end-of-life care which included a specific quality statement relating to the competence of health professionals to deliver safe and effective end-of-life care (www.nice.org.uk/guidance/qualitystandards/endoflifecare/home.jsp).

Recommendations

- ▶ **All medical schools in the UK should review their undergraduate curricula to ensure that they provide an adequate grounding in end-of-life care, as outlined in *Tomorrow's doctors*.**
- ▶ **All foundation schools should review their delivery of the foundation curriculum in relation to end-of-life care.**
- ▶ **The chairs of each specialty advisory committee should review their training curricula in regard to end-of-life care in the light of this report.**
- ▶ **Trust boards should make the delivery of high-quality care at the end of life a priority for their organisations. End-of-life care metrics should be developed, based on the End of Life Care Strategy quality markers for acute hospitals, and should be included on their management dashboards and risk registers.**
- ▶ **Commissioners and hospital trusts should consider how they can support the uptake of training in end-of-life care – for example, by using the Commissioning for Quality and Innovation (CQUIN) framework. Example standards should be based on the End of Life Care Strategy quality markers and might include specifying a proportion of physicians conducting a patient/carer survey of experience under their care, team-based learning events around death reviews and a percentage for educational uptake in a target proportion of medical staff.**

2 Methodology and remit

Following the publication of the first national end-of life care strategies for England, Scotland and Wales in 2008,²⁻⁴ many consultants in palliative medicine and other medical specialties found themselves in the position of leading the implementation in their organisations. The scale of the changes needed to implement the strategies in full are considerable and cannot, and should not, be confined to those who specialise in this area of practice. This was highlighted in the RCP's working party report of 2007, *Palliative care services: meeting the needs of patients*,¹ which also noted the variations in practice according to patients' diagnoses and marked geographical differences in access to services.

The RCP's Joint Specialty Committee for Palliative Medicine approached the Medical Specialties Board to discuss how all relevant physician groups could engage with this work. It was decided to set up a working party to:

- review the progress that has been made since 2007 and identify areas for further action
- highlight the education and professional development required for doctors to support service changes and earlier identification of the end-of-life care needs of their patients
- identify and recommend approaches to address education, training and development needs, primarily of consultant physicians and medical non-training grade doctors, including identifying strategies for providing and enhancing uptake of educational opportunities in end-of-life care
- improve the quality of end-of-life care for all patients.

Experts were selected from the membership of the original working party in 2007, supplemented by representatives from the APM, National End of Life Care Programme Board, Joint Specialty Committee in Palliative Medicine and British Geriatrics Society, as well as a consultant in learning and teaching.

The remit of this working party built on the work done in 2007, which had a much larger authorship and included many relevant specialties. This working party's membership was kept small but set out to ensure that as many physicians as possible had the opportunity to contribute to the findings. A representative from the British Geriatrics Society was included because elderly medicine has such a major contribution to make both to care delivery and education and to training in end-of-life care.

The working party identified some evidence that would be useful in developing recommendations about professional development. This included:

- literature relating to educational theory and changing culture in large organisations
- a survey from 2008 commissioned by the NAO to report on doctors' skills and training in end-of-life care.⁵ Although this was a helpful resource, most respondents were GPs or emergency/intensive care physicians and the working party wanted to access the views of a wider range of senior hospital physicians.

Evidence was gathered from as broad a range of physicians as possible. The following methods were used:

- A new electronic survey was undertaken. This was aimed at hospital consultants, staff and associate specialists, and registrars within one year of obtaining their certificate of completion of specialty training (CCT) in the UK. The survey explored how confident and competent clinicians felt in various areas of end-of-life care, what training they had accessed and how they would prefer to receive professional development in the future. It also covered perceived barriers to training about end-of-life care and examples of good practice. The survey was designed by the working party in conjunction with the RCP's

Medical Workforce Unit and was released through SurveyMonkey, with requests to members of all medical royal colleges and a reminder after one month. The survey results are reported in chapter 6.

- Telephone interviews were conducted with 15 physicians who responded to the electronic survey and volunteered to be contacted for further information. The telephone interviews were designed to generate more in-depth responses to areas highlighted in the survey. Working party members acted as interviewers, using a series of semi-structured questions emailed to the respondents in advance, along with a consent form.
- Two focus groups were run to test some of the earlier findings and elicit more detail in the responses. One was conducted with geriatricians following an afternoon symposium on 'Working together – partnerships in end of life care for the older people'. In response to an invitation, eight people attended, comprising consultant geriatricians and old-age psychiatrists and one general practitioner with a special interest in older people. The second group followed an RCP 'Regional update in medicine' and included seven consultants and two registrars from a wide variety of specialties across Yorkshire and the Humber. For both groups, verbal consent was obtained and a list of questions and prompts was used.
- Themes were drawn from the qualitative evidence, which was recorded in free text in the electronic survey and in detailed contemporaneous notes from the telephone interviews and focus groups. This was done by the consultant in learning and teaching, who has significant training and experience in the field. The emergent themes were tested in subsequent interviews and groups. Where conflicting opinions were expressed, both have been included.
- Early drafts of the report were shared with the director of the National End of Life Care Programme, carers and palliative care nursing colleagues, and their comments were incorporated in the text.
- Current provision of CPD was reviewed by searching the RCP's database of approved courses and seeking examples of good practice. Results are reported in chapter 5.

As robust evidence from published literature was not available, this report is based on consensus using the evidence listed above.

The working party met three times for 2 hours each and had three conference calls during the preparation of this work. The work was completed over a 9-month period. The draft report was sent for consultation to the leads of medical specialties at the RCP, the Professional Development Committee and the Executive Committee of the APM, the curriculum lead of the UK Foundation Programme, the GMC, the patient and public involvement group at the RCP, and the National End of Life Care Programme.

The impact of this report will be assessed in 2013–14 by a survey of hospital-based palliative care teams about the uptake of the recommendations in their trusts, the use of prompt tools in clinical practice, and a review of courses approved for CPD by the RCP. Examples of effective change that are identified will be disseminated back through hospital-based palliative care services and the Medical Specialties Board in order to trigger wider uptake.

Working party remit

This working party was set up to review what professional development is available to support physicians in this area of practice, what physicians see as their priorities, and the types and styles of learning that are most valued, and then to recommend how these can be enhanced in practice. The report describes the current workload for consultant physicians and final-year registrars in end-of-life care, where this is not their main specialty focus. It considers the importance attached to this area of work, uptake of development opportunities, and areas where physicians feel confident or in need of further support. It provides practical recommendations on how to prioritise and address the issues raised that should be taken up by individuals and organisations to improve this area of care.

3 Issues clinicians face in delivering high-quality end-of-life care

Defining end-of-life care and deciding when the focus of care should change is fraught with difficulties. For some people there will be a clear transition point in their illness – days, weeks or months before they die; some may face a general deterioration over months or years; while others die suddenly and unexpectedly. The recognition that someone is entering the last phase of their life is pivotal to eliciting patient priorities for treatment and care and balancing therapeutic burdens and benefits. Doctors may fear charges both of therapeutic nihilism or futile overtreatment. For the purposes of this report, end-of-life care is taken to start from the time when a condition (or combination of conditions) is no longer curable, when there is irreversible deterioration over a period of time and when there is a clear risk of death in the following months to a year or so.

Timely open discussions with patients and carers about the aims and limitations of treatment can enable people to consider their priorities for care. When given this opportunity, more patients and carers would choose care at home and more would achieve their wish to die in their usual place of residence when the time comes.^{22,23} However, many people will continue to die in acute hospitals for clinical and practical reasons or because of changes in patient or carer choice. There is evidence of the need to improve care during the last days in hospital in addition to avoiding hospital admission or facilitating discharge for patients who choose to die at home.²⁴ The National Confidential Enquiry into Patient Outcome and Death (NCEPOD)'s report *Caring to the end?*, which was published in 2009, reviewed the notes of more than 3,000 patients who died within four days of admission to hospital.²⁵ It highlighted differences in groups of patients admitted for terminal care (largely those with cancer) and those whose doctors expected them to die but who were not admitted for terminal care (largely with non-cancer diagnoses). Involvement of palliative care was less frequent in those not admitted for terminal care, and these patients were also much less likely to have discussions about withdrawal of treatment. This suggests that physicians find it particularly difficult to initiate discussions about end-of-life care with patients with non-malignant disease.

Trust boards are in a position to emphasise, through their clinical governance structures, that high-quality end-of-life care is part of the core business of the organisation. Creation of a supportive culture is essential to help doctors in this area of practice, which many find particularly challenging.

The use of tools to support end-of-life care has increased in recent years, becoming routine in many areas. The document *The route to success in end of life care – achieving quality in acute hospitals* emphasises the need to introduce tools systematically and to invest in training staff on their proper use.¹⁵ The most widely used tool at present is the Liverpool Care Pathway for the Dying Patient (or equivalent), which provides guidance for the care of people in the last hours or days of life (Marie Curie Palliative Care Institute: www.mcpcil.org.uk/liverpool-care-pathway). Use of the Liverpool care pathway has been the subject of three national audits between 2006 and 2011, with 115 trusts submitting data in 2009 out of a possible 159 that provided relevant services. Participating trusts can benchmark the quality of the different aspects of terminal care they deliver, which enables staff to direct their professional development to areas highlighted as needing improvement.²⁶

Specialist palliative care services support patients with complex needs from any diagnosis and at any appropriate stage of their illness, but most medical care in the last year of life is delivered by physicians from a range of specialties and by GPs. As such, end-of-life care is part of most doctors' core business and should be supported by relevant training and CPD.¹¹

Access to training and education varies across specialties and by region. By developing the knowledge and skills of senior doctors, improvements can be made to support effective decision-making about treatment

and care options. The need to address this issue explicitly and formally was highlighted in the End of Life Care Strategy in 2008.²

Recommendations

- ▶ **Senior management support is critical to enable professional development in end-of-life care. This must include:**
 - provision of time for learning
 - appropriate appraisal systems that encourage continuing professional development in end-of-life care
 - an organisational culture which values quality of care at the end of life.
- ▶ **Medical consultants should provide leadership in establishing opportunities for professional development in end-of-life care in their own settings, including agreeing how best to implement this as a department/directorate and across the trust.**
- ▶ **In order to influence their practice and ensure that patients have time to adjust, physicians must recognise that end-of-life care is not just care in the last few hours and days but that it marks the last phase of life, which may be many months or sometimes years.**

4 Educational approaches to professional development in end-of-life care

High quality end-of-life care is a multiprofessional process that requires not only clinical knowledge but appropriate attitudes, sensitive behaviours and excellent communication skills. Professional development and training programmes should therefore incorporate educational approaches that have been demonstrated to deliver effective learning in these areas.

Strengthening multidisciplinary and multiprofessional teams

Active encouragement of multiprofessional collaboration can be used successfully to ‘modify negative attitudes and perceptions’ and ‘remedy failures in trust and communication’ between professions and disciplines,²⁷ both of which can result in improved patient care. Where the primary purpose is to improve awareness of different roles and communication within teams, the most effective approaches would involve real patient scenarios – for example, in mortality and morbidity meetings. However, the Health Professions Council cautions that the ‘profession specific skills and knowledge must also be adequately addressed’.²⁸

Developing communication skills

‘Communication skills are not an optional extra; without appropriate communication skills our knowledge and intellectual efforts are easily wasted.’²⁹ Effective end-of-life care requires highly developed communication skills, which are best developed through experience supported by flexible and interactive approaches to learning – for example, observation, simulation, practice, feedback and reflection on experience.³⁰

Learning from clinical practice

End-of-life care is covered in undergraduate and postgraduate programmes to varying degrees depending on the specialty. However, most professional development in end-of-life care is gained through interactions in clinical practice. Supportive educational approaches such as bedside teaching, ward rounds, and mortality and morbidity meetings can build on existing knowledge, providing new insights and helping to develop problem-solving and reflective skills.^{30,31}

Learning from patients and carers

Feedback from patients is recognised as a valuable means of understanding patient perspectives; however, involving users in end-of-life care can be complex and challenging.³² Structured interactions with selected caregivers have proved a powerful approach to challenging misconceptions about end-of-life care, as well as to understanding the practical and psychological support needs of patients and carers.³³ Postal surveys such as the VOICES questionnaire,³⁴ which has been validated for use with bereaved relatives, can provide important feedback on services from a wide range of people.

Developing competence and confidence

Physicians tend to self-select to participate in professional development in end-of-life care. However, studies have found evidence to suggest that competence in personal performance does not always link directly with confidence, with those who are unskilled at a task being more likely to overestimate their ability.^{35–37}

Opportunities for professional development in end-of-life care should be embedded in courses, conferences, seminars and other professional development events in order to extend the reach to those who would not self-select for such training.

Disseminating innovations and effective practice

Professionals face the challenge of needing to continually update their knowledge and embrace new approaches. Specialist palliative care clinicians need to be skilful educators who are able to support colleagues in developing their knowledge and skills in end-of-life care, using a range of flexible and creative approaches.³¹

Promoting cultural change in organisations

Cultural change in relation to end-of-life care is needed in the UK. Organisational change has been shown to be more likely to succeed when the change is clearly identified, when criteria for success (both short and long term) are identified, when there is leadership at all levels, when the message is clearly communicated, when there is positive gain for all stakeholders, and when the change is supported by respected champions.

Recommendations

- ▶ **Professional development for end-of-life care should:**
 - strengthen multiprofessional teams and promote collaboration between team members
 - support the development of effective communication skills through interactive approaches such as simulation, observation and practice with feedback
 - use opportunities in routine practice to draw on clinical experiences with a direct relevance to patient care, developing problem-solving and reflective skills
 - actively seek engagement with, and feedback from, patients and caregivers to improve understanding of the patient experience
 - be embedded into a wide range of educational events such as conferences, workshops and study days, not just those that specifically focus on end-of-life care.
- ▶ **Teams involved in end-of-life care should actively plan for cultural change in the delivery of care at the end of life by identifying medical leaders, engaging colleagues, and supporting the development of expertise among colleagues.**
- ▶ **Specialist palliative care clinicians should develop wide-ranging educational skills in supporting colleagues through formal and non-formal learning by:**
 - using structured interactive events
 - facilitating effective bedside teaching
 - conducting joint ward rounds
 - mentoring colleagues
 - facilitating mortality and morbidity meetings.

5 The need for and provision of CPD across the UK

The End of Life Care Strategy identifies three groups of staff with regard to professional development needs in end-of-life care:²

- Group A – staff who work in specialist palliative care and hospices
- Group B – staff who frequently deal with end-of-life care as part of their role, eg secondary care staff who work in accident and emergency, acute medicine, respiratory medicine, care of the elderly, cardiology, oncology, renal medicine, intensive care, and those who work with patients with long-term neurological conditions
- Group C – staff who work within other services and who infrequently have to deal with end-of-life care.

Four areas were identified as common core requirements for the workforce:

- training in communication skills
- assessment of a person's needs and preferences
- advance care planning
- symptom control.

The professionals in Group B should be given a high priority in terms of CPD, with particular emphasis on training in advanced communication skills for staff who may initiate discussions with patients about end-of-life care issues.

To assess the number and type of CPD opportunities open to physicians, an analysis of approved CPD events for palliative and end-of-life care between 1 April 2006 and 1 October 2011 was undertaken using the RCP database for approved CPD. Local events and those aimed primarily at junior doctors are likely to have been missed, as the organisers of such events would not usually apply for CPD approval. The analysis of activities over the 4.5-year period identified 1,298 activities, 1,233 of which were eligible (those provided by commercial organisations were excluded). Country of origin, type of provider organisation, type of educational event and the medical specialties that events were approved for were ascertained (Tables 1–3).

Table 1 Approved CPD activities in end-of-life care by country of origin

Country of origin	Number of approved CPD activities
Scotland	82
Wales	52
Northern Ireland	17
England	1,082

For palliative medicine physicians, there were 120 events, most of which were regional training or physician meetings. Most CPD events also open to other physicians were on advanced communication skills training (28%). Eight per cent of these events could be linked to pain and symptom management, which may also have been embedded in the 79 palliative care conferences (6.5%).

Table 2 Approved CPD activities in end-of-life care by type of organisation

Type of organisation	Approved CPD activities	
	Number (%)	Notes
NHS trust or equivalent	438 (35)	
Cancer network	332 (27)	Most (n=309) were for advanced communication skills training
Hospice	278 (23)	80% were from the voluntary sector
Specialist society	94 (9)	Wide spectrum of societies, most of which were linked to non-cancer diagnoses (see Table 4), with 29 specific to the APM
Academic institution	60 (5)	
Deanery	15 (1)	Educational supervision, appraisal and teaching skills
Not specified	16	

Table 3 Approved CPD activities by type of educational event

Type of educational event	Approved CPD activities	
	Number (%)	Notes
Communication skills training	340 (28)	Most initiated via cancer networks
Pain and symptom management	102 (8)	
Palliative care conferences	79 (6.5)	Open to multiprofessionals
Research	88 (7)	
Cancer	56 (4.5)	
Ethics	21 (2)	
Psychological	24 (2)	
Teaching and training	25 (2)	
Events organised by non-palliative care societies	65 (5)	
Clinical updates for doctors in palliative medicine	120 (10)	
Not specified	313	

During the survey period, no approved events in palliative care were aimed specifically at physicians who were not palliative medicine specialists, although two joint study days on breathlessness and fatigue were run at the Royal College of Physicians in London. It was difficult to identify CPD entries linked to advance care planning. Only 5% of events were linked specifically to long-term conditions despite the high associated mortality (Table 4).

Table 4 Non-cancer CPD events with palliative care content

Type of educational event	Approved CPD activities
Diagnosis	Number n=47 (5%)
Renal	5
Cardiac	5
Neurological disorders	17
Respiratory	4
Dementia	1
Elderly care	1
Stroke	3
HIV	2
Learning disability	1
Nutritional medicine	8

Recommendations

- ▶ The Royal College of Physicians and specialist societies should promote the inclusion of end-of-life care within study days and conferences related to long-term conditions.
- ▶ Training in advanced communication skills for physicians who care for those with long-term conditions should have equal priority and resources as the training required for those involved in caring for patients with cancer.
- ▶ Local palliative care providers should work with the palliative and end-of-life care networks to deliver more extensive and targeted CPD for physicians.

6 Evidence gathered from physicians

Survey*

The online survey received 1,846 responses;³⁸ this compares favourably with the NAO's survey from 2008, which reported 901 completed replies.⁵ Despite the large number of responses, it must be acknowledged that the survey reflects the views of a self-selected group of clinicians. However, the demographics suggest that they are representative of the geographical areas and gender differences (2:1 male to female) that would be expected in the whole population of consultants, doctors in non-training grades, and registrars within one year of obtaining their CCT. As would be expected, the split between male and female respondents was more even in the group of registrars. The distribution by SHA was similar to that in the NAO's survey⁵ and in data from the RCP's census of consultants in 2010 (RCP: www.rcplondon.ac.uk/resources/2010-census-summary), with SHAs in London best represented and those in the South East Coast least well represented.

The survey seemed to reach the target audience in terms of grade of doctor and specialty. Consultants made up 61.1% of respondents, registrars 34.3%, and specialty and associate specialist (SAS) doctors 4.8%. We analysed data separately for consultants and registrars to see whether there was a discernable difference between these groups. By and large the results were similar; where they differed we have made a comment. There was a good spread of medical specialties; although there was some dissemination outside our target population, this only amounted to around 2% of the total. The vast majority of doctors identified themselves as being in acute hospital medical specialties; geriatricians made up the majority (Fig 1). The proportion of patients eligible for end-of-life care in our survey was similar to that in the NAO's survey, with about half of doctors identifying less than 10% of their patient population as in this group (Fig 2).

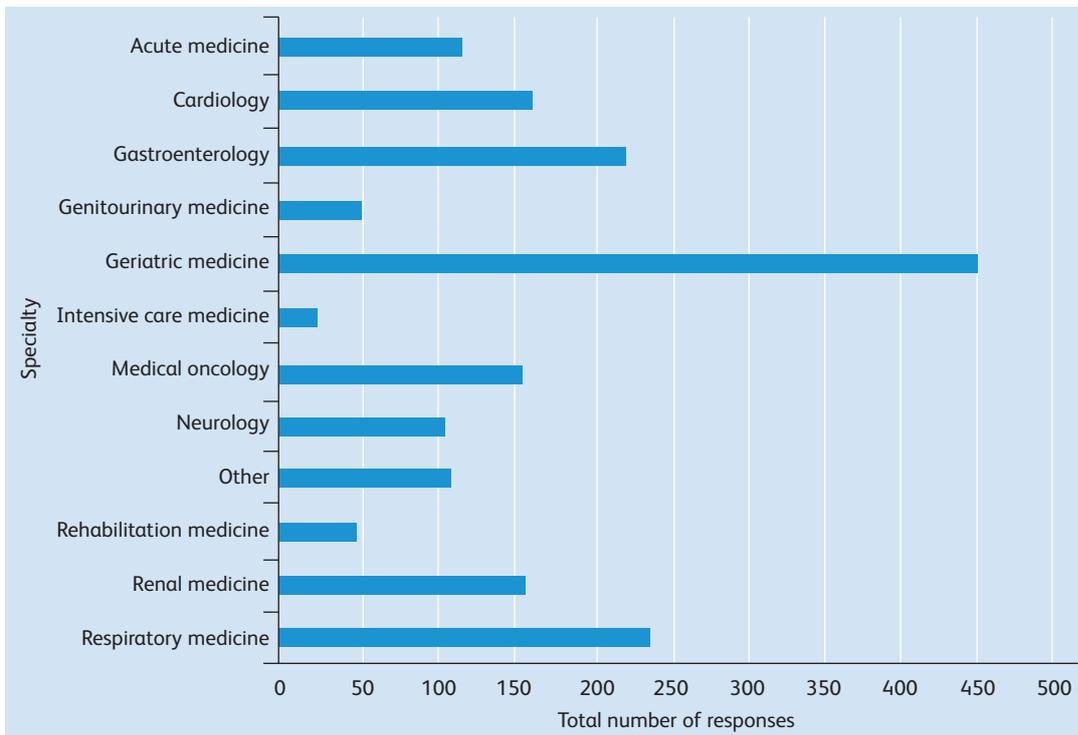


Fig 1. Responses to survey question: 'What is your specialty?'. Source: RCP End-of-life care survey 2011.³⁸

*Complete survey results are available at www.apmonline.org and www.rcplondon.ac.uk/resources/improving-end-of-life-care-professional-development-for-physicians.³⁸

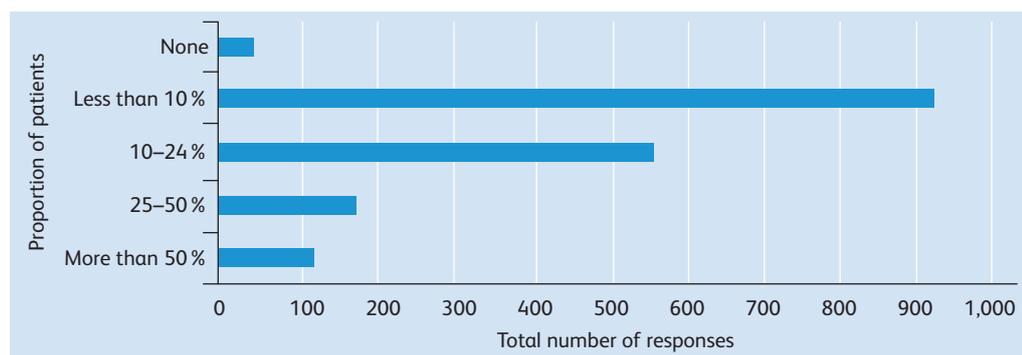


Fig 2. 'Please estimate the proportion of patients whose care you were involved with in the last 12 months who would have been eligible for end-of-life care.' *Source:* RCP End-of-life care survey 2011.³⁸

Self-rating of confidence and competence in providing end-of-life care

Respondents were asked to rate their confidence and competence on a scale of 1–10 for a number of items (Table 5 and Fig 3). They reported high levels of confidence in the provision of end-of-life care, including recognising when a patient entered this phase and discussing it with the patient and their family. Doctors felt highly competent in breaking bad news, pain control, and withholding and withdrawing treatment. Areas with the lowest reported competence included end-of-life care in dementia, other symptom control, and advance care planning. For most of the questions, there was a trend towards greater confidence/competence for consultants than for registrars. Similarly, consultants were more likely to identify that their training had prepared them well to provide end-of-life care (Fig 4). The survey was not set up to test skills in providing end-of-life care, and, as already discussed, high levels of confidence do not necessarily indicate high levels of competence.

Table 5. Competence/confidence in providing different aspects of end-of-life care (1 = not competent/confident at all, 10 = extremely competent/confident).

Item	Competence/confidence
Breaking bad news	9
Dealing with distressed families	8
Pain control	8
Other symptom control	7
Arranging discharge at the end of life	8
Withdrawing/withholding treatment at the end of life	8
Advance care planning	7/8
End-of-life care in dementia	7

Source: RCP End-of-life care survey.³⁸

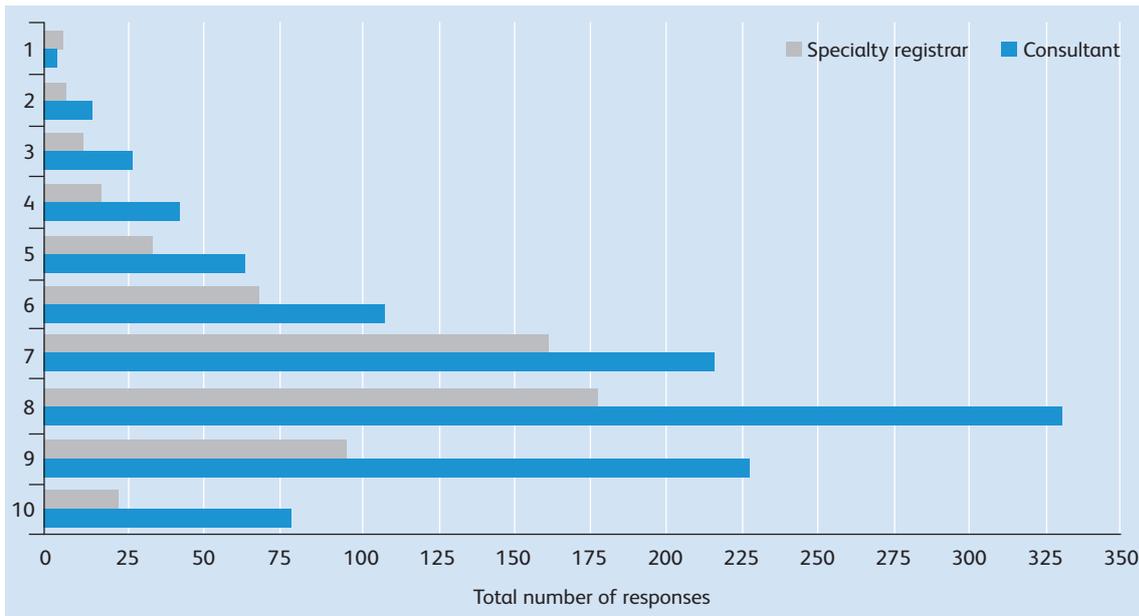


Fig 3. ‘How would you rate your confidence in discussing end-of-life care with those who are approaching the end of their lives?’ (1 = not confident at all; 10 = extremely confident). *Source:* RCP End-of-life care survey 2011.³⁸

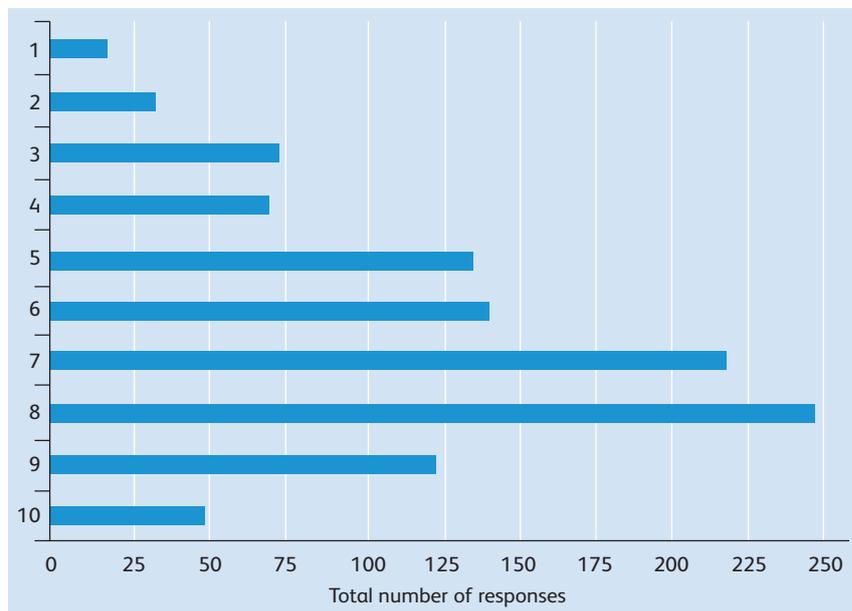


Fig 4. ‘How poorly or well do you feel your training so far has prepared you to deliver end-of-life care to patients and families?’ (Grade: consultants; 1 = not at all well prepared; 10 = extremely well prepared). *Source:* RCP End-of-life care survey 2011.³⁸

Opportunities for professional development in end-of-life care

Two thirds of respondents reported that they had not attended any professional development event on end-of-life care in the last 5 years. This is surprising given the recent focus on end-of-life care, the development of tools for managing the last days of life in acute trusts, advance care planning,³⁹ and new guidance from the GMC published in 2010.¹¹ However, this may reflect how respondents define end-of-life care: whether they only consider end of life as the last days and weeks and whether they consider end-of-life care as separate from palliative care.

Seminars were the most usual/popular event identified and conferences the least popular. The majority providers were NHS trusts, and most events attended were up to 3 hours in duration. The most common topics were the use of end-of-life care tools and ethical issues, followed by pain and symptom management. Interestingly, advance care planning was less commonly the topic of attended events. ‘Other’ topics identified revealed a pattern of disease-specific professional development events that included end-of-life care as part of the day. Most common among these were renal medicine courses, but there were also courses with the main topics of cardiology, elderly medicine, dementia and Parkinson’s disease. Psychological support and spiritual support were identified as the focus of a number of events, as was strategic planning.

Complaints and critical incidents featuring end-of-life care were reported as relatively low, although there was a broad spread. This is in contrast to the Healthcare Commission’s finding that 50% of unresolved complaints in acute trusts are related to care at the end of life.⁴⁰ However, these data have been challenged by more recent research reported by the National End of Life Care Programme, which put the figure at 4% of all complaints in four trusts over a 6-month period.⁴¹ Specialist registrars associated end-of-life care with critical incidents or complaints to a greater degree than consultants. The results suggest that critical incident reporting and complaint reviews could be used to raise awareness of issues relating to end-of-life care. Morbidity and mortality meetings, notes reviews and complaint reviews are all possible means of learning.

Respondents rated the importance of professional development in end-of-life care highly in terms of their overall CPD (Fig 5). However, the support received from their trust or local organisation to provide training for themselves and other staff and to embed it into routine practice was rated less highly (Fig 6):

‘These courses are too few. My specialty is liver cancer, so I deal with palliative care related issues on a daily basis, having never had any “formal training”. My own trust has arranged one event in the last 5 years, but it was oversubscribed and I could not get a place. More frequent shorter sessions would be helpful, or regional half or one-day meetings rather than having the expense of trips to London, especially if [an] overnight stay was involved.’

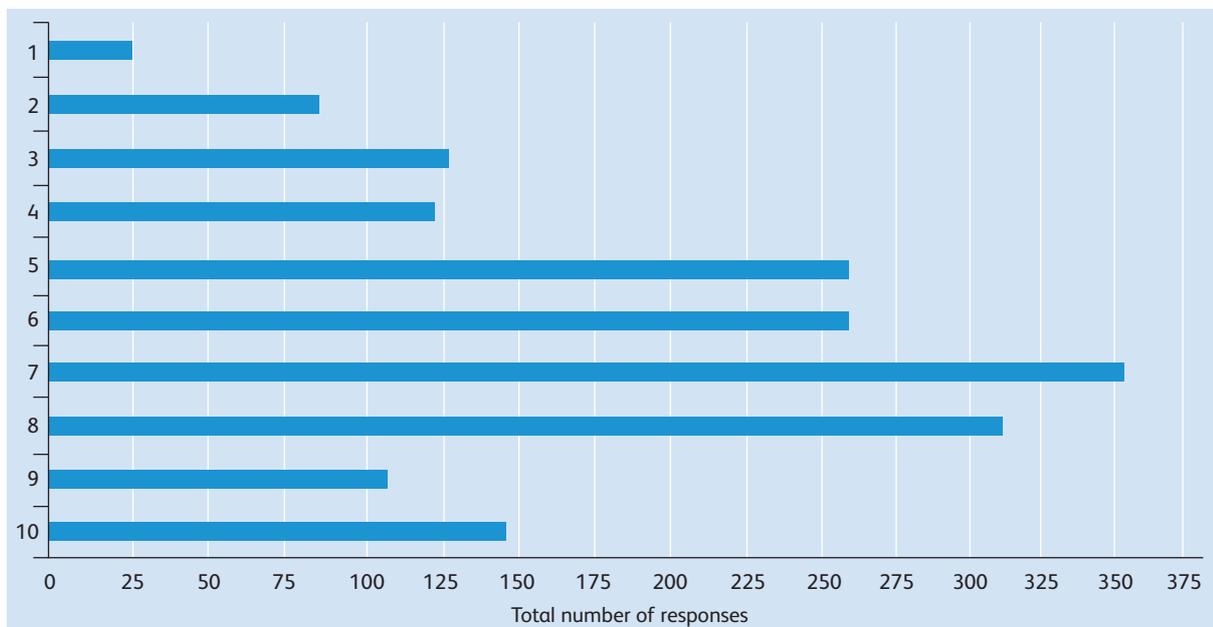


Fig 5. ‘Where would you rank the importance of professional development in end-of-life care in terms of your overall CPD?’ (1 = not important; 10 = highly important). Source: RCP End-of-life care survey 2011.³⁸

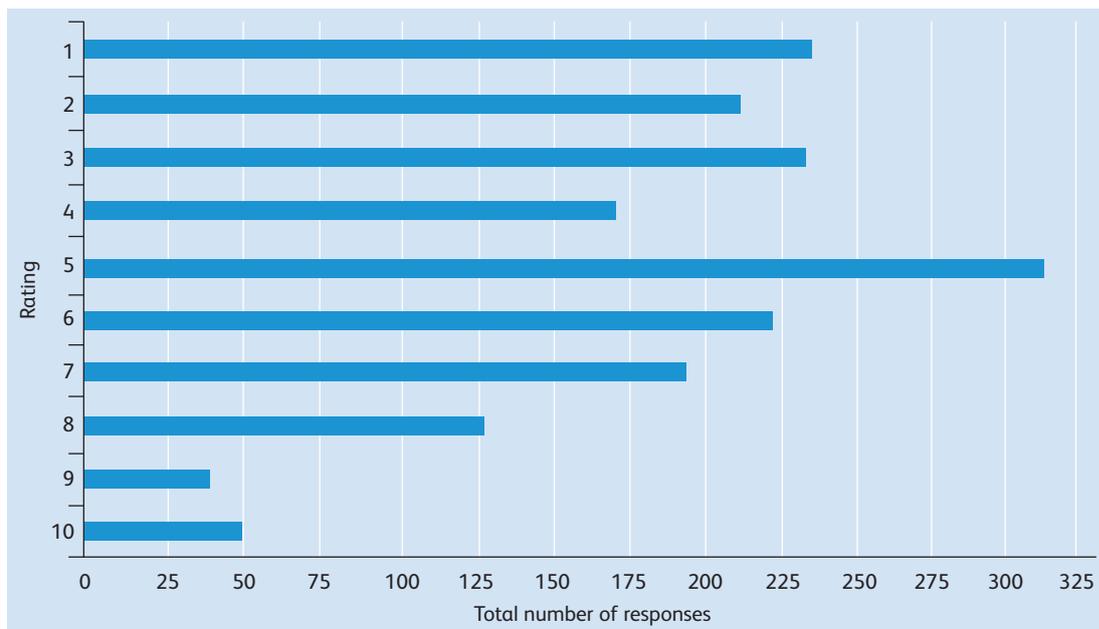


Fig 6. 'How much do you think your trust/organisation has done to support end-of-life education for you?' (1 = nothing at all; 10 = fully supportive). *Source:* RCP End-of-life care survey 2011.³⁸

When respondents were offered a choice of professionals as their educators, consultants in palliative medicine were preferred. Registrars were more open to being taught by registrars in palliative medicine than consultants. The next most-favoured educators for both groups were palliative care clinical nurse specialists. There was less enthusiasm about receiving training from general physicians or GPs with a special interest.

Future professional development

When asked how they would prefer to access professional development in the future, less than 10% of respondents wanted to attend events that lasted longer than a day. Trust-run courses were identified as the most popular source for day-long courses. For periods of time less than 3 hours, respondents ranked in descending order: e-learning, morbidity and mortality meetings, educational literature such as the *Clinical Medicine* journal, and clinical governance events.

Other suggested opportunities for learning were specialty-specific meetings that include end-of-life care as a part of the course or conference, departmental meetings that include joint meetings with the palliative care team, on-the-job training from palliative care professionals and placements with the palliative care team. Several comments suggested that mandatory training in end-of-life care would not be welcome.

'There is limited need to devolve this from good standard care provision. Updates should be around changes in law, new symptom control medications/evidence. Short targeted workshops and seminars/presentations occasionally is all that is needed. It is not necessary to have yearly mandatory CPD requirements in this specifically.'

Barriers to end-of-life care training

Of the potential barriers we had identified, limited time for training was acknowledged by 70% of respondents. Availability of courses and teaching was identified as a barrier by 45%, with accessibility and cost also rating highly. Only 1.7% of respondents felt that you cannot teach this type of care and only 3.1% that teaching in end-of-life care would not help their practice. Our respondents did seem to recognise that developing themselves in this area is important.

Examples of good practice and other comments

The presence of a supportive palliative care team was identified as an important source of professional development, as well as being important for provision of good end-of-life care. Placements with a palliative care team were highly rated; most comments reflected an opportunity taken during training. However, doctors also stated that good end-of-life care was part of their role and that they learnt from experience (including the death of relatives) supplemented by private study and common sense.

'Availability and contact with the palliative care team has proved the most effective agent for change.'

'Our palliative care [team] is very proactive and has regular slots at our hospital teaching sessions in medicine; they also do a lot of ad-hoc/opportunistic teaching on the ward.'

'I believe our end-of-life care has been improved by the integrated care provided by the palliative care team with joint ward rounds. This has been far better than any training course.'

'I strongly believe that [end-of-life care] is best taught clinically – by observation and mentoring. I think a short stint in a palliative care ward/hospice is almost compulsory for any clinician who would be dealing with patients approaching their end of life. My 8 weeks as a locum palliative care SpR threw me in the deep end but provided me with a breadth of experience that no taught course or e-learning module will ever be able to.'

'I worked as a palliative care registrar in Australia, which was very valuable. I think all medical registrars in the UK should have similar [experience].'

There were some comments from clinicians who found palliative care teams either unavailable or unhelpful.

The reality is that the specialists in palliative care are a) not very available when needed [and] b) often not very helpful.

A number of respondents commented that they found discussion of cases at departmental meetings a useful way of continued improvement in end-of-life care.

'At our 3-monthly morbidity and mortality meetings, all deaths are reviewed and stratified for risk. This includes highlighting when aspects of an expected death were not perfect.'

'Departmental reflection on end-of-life care in mortality [is] part of clinical governance meeting[s].'

The Liverpool Care Pathway for the Dying Patient (LCP) was identified as a driver for improved recognition of patients at the end of life in several settings.

'Our unit recently implemented the Liverpool care pathway and this has greatly improved the recognition of the dying patient and improved the patient's and family's care.'

However, there were also a number of negative comments about the LCP and other pathways, which suggests that careful implementation of such tools is as important as the documentation itself in ensuring that staff have a good understanding of their use.

The value of multidisciplinary and multiprofessional collaboration was highlighted by some respondents.

'Keep it multidisciplinary – everyone shines a different light on the problem.'

Telephone interviews

Fifteen telephone interviews were conducted with senior physicians (12 consultants, two registrars and one clinical fellow). Seven of the interviewees were geriatricians; the remaining participants were spread between internal medicine, respiratory medicine, cardiology, neurology, gastroenterology, medical oncology and intensive care medicine. Results are presented together with themes from the two focus groups.

Interviewees had a wide range of definitions and understanding of end-of-life care, identifying the last days of life and an indeterminate period of time before that. In addition, interviewees recognised that a feeling of professional failure can be associated with a diagnosis of dying, which may overshadow the appreciation that this can lead to greater involvement of patients and families in choices about their priorities for care in the face of the inevitable.

'[There is a] barrier to making [a] diagnosis of end-of-life care as [I am concerned that] it becomes a self-fulfilling prophecy.'

We asked about competence and confidence in areas related to end-of-life care. There was some discussion about the relationship between the two: 'Confidence and competence don't always go together – you can have one without the other!' Areas of least confidence identified by this group included advance care planning, managing adults who lack capacity, and holding discussions about withholding cardiopulmonary resuscitation.

Participants identified informal learning, including departmental audit and clinical or personal experience, as good sources of development. Next to that, the most frequently mentioned source of learning was role models, including palliative care teams. As in the online survey, there were also comments from telephone interviews and the focus groups about palliative care teams not being sufficiently available or amenable to assist with end-of-life care.

'I am very lucky to have support from [a] great palliative care team.'

'In my experience palliative care specialists do not have much interest in providing end-of-life care for the majority of people that die. I am afraid they prefer to remain in the ivory tower and just look after the small proportion of people who die in hospice settings.'

Most respondents identified that courses purely aimed at end-of-life care may not be the best way to learn or the most attractive to general physicians, although communication skills and breaking bad news were identified as areas that require specific training.

'Most of my colleagues would not go to a separate palliative care conference'... 'opportunity is to integrate [end-of-life care] learning into the major conferences...they would all go to the plenary lectures'

'The thing is how you get palliative and end-of-life care into mainstream care.'

Another theme that emerged was the difficulty in identifying what is happening in primary care and the need for joint working between the acute sector and community services – both to facilitate good care and for professional development. One respondent had a joint conference with community professionals on end-of-life care and had been encouraged by the attendance and enthusiasm of GPs.

'Having meetings with primary and secondary care representatives...this would also be an opportunity for two-way education through this meeting'

'Working in hospital...less aware of what GPs can do, and updates about this would be useful'

'[It is] sometimes a bit of a gamble when you send people home to die.'

Many interviewees stressed that it was difficult to develop these skills in other people. Working with junior staff to embed this into the culture of care was likely to be more productive than trying to change the way consultants approach things. Modelling 'good' behaviour and encouraging junior staff to reflect on what they had seen was regarded as important. Mentoring and the 'apprenticeship' approach were mentioned as the most powerful methods of learning.

Focus group discussions

Additional themes that came out strongly from the focus groups were:

- Active treatment and palliative care can coexist but it takes courage and experience to manage patients in this way and explain the approach to patients and their families.

- Disjointed care with multiple handovers is not conducive to ‘standing back and looking at the patient, rather than treating the pathology’. Routine use of general and disease-specific prognostic indicator tools may help with this.^{42,43}
- There is a tendency to treat the presenting complaint and discharge the patient quickly rather than to see them as someone likely to be in the last weeks or months of life and then open a conversation about their preferences for care.
- Approaching conversations about end-of-life care is more difficult in patients with non-malignant diagnoses, as both patients and their doctors see cancer as a terminal illness but this is not always the case with other conditions, such as severe heart failure.
- There are ‘always good reasons not to initiate difficult conversations’ and it is easier to ‘break bad news than to discuss uncertainty’.
- Routine questions as part of the post-take ward round may be useful in prompting further discussion. Such questions may include: ‘Is this patient at risk of dying during this admission? If so, have you discussed this with the patient and asked about their preferences for care in the event of their deterioration?’
- There was broad agreement that many out-of-hours calls from junior staff to consultants were about ‘the focus of care and how active to be’; consultants welcomed this and saw it as an opportunity for teaching.

There was recognition that good end-of-life care should not be seen as ‘giving up’ but rather as ‘giving alternatives’. A structured approach to the management of such patients – akin to the Liverpool Care Pathway for the Dying Patient but earlier in the course of an illness – would be very helpful. The AMBER care bundle (Assessment, Management, Best Practice, Engagement of patients and carers, for patients whose Recovery is uncertain), devised and introduced initially by Guy’s and St Thomas’ Foundation Trust, provides such a structure for patients in hospital for whom recovery is uncertain.⁴⁴ This involves a four-part process:

Within 4 hours of identifying a patient whose recovery is uncertain:

- (1) a clear medical plan should be recorded in the hospital notes
- (2) a clear escalation plan should be recorded in the hospital notes
- (3) nursing staff should have understood and agreed the plans
- (4) within 12 hours, a patient/carer meeting or discussion should have been organised, conducted and documented.

The plan should be reviewed daily.

Themes that came out from those working with older people were that dementia is particularly challenging because this condition does not start at one particular time and patients often cannot be involved directly in decision making. Geriatricians may be reluctant to refer to palliative care as it is seen as associated with cancer and with withdrawal of treatment. Some participants assumed that active treatment cannot coexist with symptomatic treatment or palliative care. These issues and the difficulty in judging prognosis for these patients meant that dying was often diagnosed too late. Participants agreed that patients would find the term end-of-life care more acceptable and that specialist palliative care is not always required. They were also of the opinion that there is inequity of care and clear age discrimination in all sectors. They recommended that end-of-life care should be delivered on the basis of need rather than diagnosis; dementia must be given special attention, communication around the dying process is fundamental, and advance care planning should not be compartmentalised. Leadership and follow-through were regarded as essential.

Although participants felt largely competent and confident in carrying out end-of-life care, they would appreciate further training in all areas of palliative care, especially:

- recognition of delirium
- behavioural and psychological aspects of dementia

- end-of-life care in dementia
- dealing with unpredictability and uncertainty
- communication skills to hold early discussions
- learning to implement the ‘surprise question’; ie Would you be surprised if this patient died in the next 12 months? ⁴²
- recognition of the dying process
- understanding capacity and consent and managing the legal framework
- identifying when advance care planning in dementia should start.

Although e-learning was said to be excellent, participants personally had learnt through shadowing palliative care physicians and nurses, hospice attachments, and attending courses on advanced communication skills.

Participants recommended that more training be delivered at the undergraduate and postgraduate levels using e-learning, observation, reflective practice and problem- or case-based discussions. Trainees and consultants should be encouraged to listen to patients’ stories and learn about both good and bad experiences. Multidisciplinary meetings should be promoted to provide a venue where discussion about challenging cases could take place. For example, the Schwartz round, a multidisciplinary format that originated in the USA, has been evaluated by the King’s Fund and found to be an effective way of reflecting on and changing practice.⁴⁵ Advanced communication skills courses and compulsory courses using the GMC’s guidelines were thought to be helpful. Sponsorship from the RCP could ensure take-up and peer respectability.

Recommendations

- ▶ **Reflection and learning on end-of-life care should be integrated with daily clinical practice. This may be done through directorate meetings; structured multidisciplinary meetings; morbidity and mortality meetings; joint ward rounds and outpatient clinics with palliative care colleagues; grand rounds; mentoring; and placements.**
- ▶ **Hospital palliative care teams should be available in each hospital and should be resourced to lead the delivery of professional development in end-of-life care. As experiential learning is most valued, this should include time to work with colleagues in clinical practice and to provide clinical placements and mentorship.**
- ▶ **Hospital palliative care teams should include leading professional development in end-of-life care as an integral part of their role. This should include providing support as well as working with staff from other disciplines and professions to learn with, and from, them.**
- ▶ **The role of hospices and specialist palliative care units/teams in providing experiential placements for physicians should be recognised and resourced.**
- ▶ **The use of e-learning, such as End of Life Care for all (e-ELCA), to support work-based learning should be included where relevant.**
- ▶ **Consultants who provide care at the end of life should incorporate this into their continuing professional development (CPD) and undertake at least one learning event in end-of-life care within a 5-year CPD cycle. This should be reviewed at their annual consultant appraisal.**

- ▶ Hospital trusts should review their provision of learning opportunities for their consultant, trainee and non-training grade workforce and, where necessary, increase the availability of local end-of-life care training and education.
- ▶ Tools such as care pathways for end-of-life care must be properly implemented and should receive continuing support to sustain the learning that is required, otherwise such tools can be counterproductive by encouraging a 'tick box' approach rather than promoting high-quality care.
- ▶ The introduction of systems of care that help to highlight patients who may be at risk of dying during a hospital admission, such as the AMBER care bundle or equivalent, should be considered as a tool to help professional development within teams and to guide day-to-day practice.
- ▶ Hospital and primary care teams should acquaint themselves with the range of general and disease-specific tools to identify patients with advanced illness, or who may be approaching the end of life, and consider their applicability and use within their routine practice.
- ▶ Physicians whose practice includes patients in the last phase of their lives should consider using the 'Top ten tips', 'Post-take ward round prompts' and 'Mortality and morbidity meeting prompts' provided in this report during their routine practice.
- ▶ Joint learning with GPs should be encouraged to further the understanding of each other's roles and services and to improve coordination of care across traditional boundaries.

References

- 1 Royal College of Physicians. *Palliative care services: meeting the needs of patients*. London: RCP, 2007.
- 2 Department of Health. *End of life care strategy: promoting high quality care for all adults at the end of life*. London: DH, 2008. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277 [Accessed 6 January 2012].
- 3 NHS Scotland. *Living and dying well, a national action plan for palliative and end of life care in Scotland*. Edinburgh: NHS Scotland, 2008. www.scotland.gov.uk/Publications/2008/10/01091608/0 [Accessed 6 January 2012].
- 4 Sugar V. *Palliative Care Planning Group Wales: report to the Minister for Health and Social Services*. Cardiff: Welsh Assembly Government, 2008. www.wales.nhs.uk/palliativecare [Accessed 6 January 2012].
- 5 National Audit Office. *Survey to doctors in England – end of life care*. Abingdon: medeConnect, 2008. www.nao.org.uk/publications/0708/end_of_life_care.aspx [Accessed 6 January 2012].
- 6 National End of Life Care Intelligence Network. *Variations in place of death in England. Inequalities or consequences of age, gender and cause of death?* Bristol: NEoLCIN, 2010. www.endoflifecare-intelligence.org.uk/view.aspx?rid=71 [Accessed 6 January 2012].
- 7 National End of Life Care Intelligence Network. *Predicting death: estimating the proportion of deaths that are 'unexpected'*. Bristol: NEoLCIN, 2011. www.endoflifecare-intelligence.org.uk/resources/publications/predicting_death.aspx [Accessed 6 January 2012].
- 8 Gomes B, Higginson IJ. Where people die (1974-2030). Past trends, future projections and implications for care. *Palliat Med* 2008;22:33–41.
- 9 National End of Life Care Intelligence Network. *Deaths in older adults in England*. Bristol: NEoLCIN, 2010. www.endoflifecare-intelligence.org.uk/view.aspx?rid=82 [Accessed 6 January 2012].
- 10 Department of Health. *End of life care strategy: quality markers and measures for end of life care*. London: DH, 2009. www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_101681 [Accessed 6 January 2012].
- 11 General Medical Council. *Treatment and care towards the end of life: good practice in decision making*. London: GMC, 2010. www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp [Accessed 6 January 2012].
- 12 Royal College of Physicians. *Leading for quality: the foundation for healthcare over the next decade*. London: RCP, 2010. www.rcplondon.ac.uk/policy/responding-nhs-reform/leading-quality [Accessed 6 January 2012].
- 13 Paes P, Wee B. A Delphi study to develop the Association for Palliative Medicine (APM) consensus syllabus for undergraduate palliative medicine in Great Britain and Ireland. *Palliat Med* 2008;22:360–4.
- 14 General Medical Council. *Tomorrow's doctors: outcomes and standards for undergraduate medical education*. London: GMC, 2009. www.gmc-uk.org/education/undergraduate/tomorrows_doctors.asp [Accessed 6 January 2012].
- 15 National End of Life Care Programme. *The route to success in end of life care – achieving quality in acute hospitals*. London: Stationery Office, 2010. www.endoflifecareforadults.nhs.uk/publications/route-to-success-acute-hospitals [Accessed 6 January 2012].
- 16 National End of Life Care Programme. *Talking about end of life care: right conversations, right people, right time*. London: Stationery Office, 2011. www.endoflifecareforadults.nhs.uk/publications/talking-about-eolc [Accessed 6 January 2012].
- 17 Ipsos MORI. *End of life locality registers evaluation. Final report*. London: Ipsos MORI, 2011. www.endoflifecareforadults.nhs.uk/publications/localities-registers-report [Accessed 6 January 2012].
- 18 NHS Kidney Care. *End of life care in advanced kidney disease: a framework for implementation*. Sudbury: Prolog, 2009. www.endoflifecareforadults.nhs.uk/publications/eolcadvancedkidneydisease [Accessed 6 January 2010].
- 19 National End of Life Care Programme/NHS Improvement. *End of life care in heart failure: a framework for implementation*. Leicester: NEoLCP/NHS Improvement, 2010. www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-for-heart-failure-a-framework [Accessed 6 January 2012].
- 20 National End of Life Programme/National Council for Palliative Care/Neurological Alliance. *Improving end of life care in neurological disease: a framework for implementation*. London: Stationery Office, 2011. www.endoflifecareforadults.nhs.uk/publications/end-of-life-care-in-long-term-neurological-conditions-a-framework [Accessed 6 January 2012].
- 21 e-Learning for Healthcare. *Welcome to e-ELCA*. e-ELCA, 2010. www.e-lfh.org.uk/projects/e-elca/launch/wel.html [Accessed 6 January 2012].

- 22 NHS Improvement. *Preferred priorities of care implementation at the Christie Hospital: early patient decision making*. Leicester: NHS Improvement, 2007. www.improvement.nhs.uk/winning_principles/principles_1/61008_4_christies_cancer.pdf [Accessed 6 January 2012].
- 23 Wood J, Storey L, Clark D. Preferred priorities of care: an analysis of the first 100 patients' assessments. *Palliat Med* 2007;21:449–50.
- 24 Mayland CR, Williams EMI, Addington-Hall J, Ellershaw JE. How well are the following symptoms being controlled in the last hours and days of life: pain, restlessness, respiratory tract secretions, breathlessness, nausea and vomiting? *Palliat Med* 2008;22:578.
- 25 National Confidential Enquiry into Patient Outcome and Death. *Caring to the end? A review of the care of patients who died in hospital within four days of admission*. London: NCEPOD, 2009. www.ncepod.org.uk/2009dah.htm [Accessed 6 January 2012].
- 26 Marie Curie Palliative Care Institute/Royal College of Physicians. *National care of the dying audit – hospitals (NCDAH). Round 2. Generic report 2008/2009*. Liverpool: Marie Curie Palliative Care Institute, 2009. www.rcplondon.ac.uk/resources/national-care-dying-audit-hospitals [Accessed 6 January 2012].
- 27 Barr H. *Interprofessional education: today, yesterday and tomorrow*. London: LTSN Centre for Health Sciences and Practice, 2002.
- 28 Health Professions Council. *Standards in education and training*. London: HPC, 2005.
- 29 Dent JA, Harden R. *A practical guide for medical teachers*. London: Churchill Livingstone, 2009.
- 30 Kaufman DM, Mann KV. *Teaching and learning in medical education: how theory can inform practice*. Edinburgh: ASME, 2007.
- 31 Wee B, Hughes N. *Education in palliative care*. Oxford: Oxford University Press, 2007.
- 32 Black J. User involvement in end of life care: how involved can patients/carers be? *End of Life Journal* 2008;2(4).
- 33 Wee B, Davies S, Holt C. Involving lay caregivers in medical education. *Med Educ* 2008;42:1111–46.
- 34 Addington-Hall J, Hunt K, Shlomo N, Richardson A. *VOICES redesign and testing to inform a national end of life care survey*. London: Stationery Office, 2011.
- 35 Kruger J, Dunning D. Unskilled and unaware of it: how difficulties in recognizing one's own incompetence lead to inflated self-assessments. *J Pers Soc Psychol* 1999;77:1121–34.
- 36 Burson KA, Larrick RP, Klayman J. Skilled or unskilled, but still unaware of it. *J Pers Soc Psychol* 2006;90:60–77.
- 37 Davis DA, Mazmanian PE, Fordis M *et al*. Accuracy of physician self-assessment compared with observed measures of competence: a systematic review. *JAMA* 2006;296:1094–102.
- 38 Royal College of Physicians. End-of-life care survey, 2011. www.apmonline.org and www.rcplondon.ac.uk/resources/improving-end-of-life-care-professional-development-for-physicians
- 39 Royal College of Physicians. *Advance care planning*. Concise guidance to good practice series, number 12. London: RCP, 2009. www.rcplondon.ac.uk/resources/advance-care-planning-national-guidelines [Accessed 6 January 2012].
- 40 Healthcare Commission. *Spotlight on complaints*. London: Healthcare Commission, 2007.
- 41 National End of Life Care Programme. *An analysis of the numbers of hospital complaints relating to end of life care over a six month period – in four hospital trusts*. London: NEOFCEP, 2011. www.endoflifecareforadults.nhs.uk/publications/an-analysis-of-the-numbers-of-hospital-complaints-relating-to-end-of-life-care-over-a-six-month-period [Accessed 6 January 2012].
- 42 Gold Standards Framework. *Prognostic indicator guidance*. Revised Vs 5. Sept 08. Shrewsbury: National Gold Standards Framework Centre, 2008. www.goldstandardsframework.nhs.uk/OneStopCMS/Core/CrawlerResourceServer.aspx?resource=B8424129-940E-4AFD-B97A-7A9D9311BC25&mode=link&guid=eae1921fd0694340841dbfc891be1047 [Accessed 6 January 2012].
- 43 NHS Lothian. *Identifying patients with advanced illness: supportive and palliative care indicators tool (SPICT)*. Edinburgh: NHS Lothian, 2011. www.palliativecareguidelines.scot.nhs.uk/documents/SPICT_October2011.pdf [Accessed 6 January 2012].
- 44 Modernisation Initiative End of Life Care. *Innovative practice: the AMBER care bundle*. Modernisation Initiative End of Life Care, 2010. www.tin.nhs.uk/EasySiteWeb/getresource.axd?AssetID=37208&type=full&servicetype=Attachment [Accessed 6 January 2012].
- 45 Firth-Cozens J, Cornwell J. *The point of care: enabling compassionate care in acute hospital settings*. London: King's Fund, 2009. www.kingsfund.org.uk/current_projects/point_of_care/schwartz_center_rounds.html [Accessed 6 January 2012].

Appendix 1 Top ten tips for physicians

- 1 **Integrate palliative care into your daily practice** – ask a member of your palliative care team to attend clinics, ward rounds and multidisciplinary team meetings, especially in areas with a high proportion of patients who require palliative care.
- 2 **Adopt the ‘prompting tool’ during the post-take ward round** to help identify patients who require supportive care (see Appendix 2).
- 3 **Adopt the ‘prompting tool’ during mortality and morbidity meetings** to see whether patients’ choices for type and place of care were ascertained in a timely way and acted upon (see Appendix 3).
- 4 **Actively incorporate feedback from patients and carers** to guide your professional development.
- 5 **Refer to your local palliative care guidelines** for quick reference and a stepwise management guide to common palliative care problems.
- 6 **Include at least one learning event on ‘end-of-life care’** within a 5-year continuing professional development (CPD) cycle.
- 7 **Find an up-to-date list of useful courses on palliative and end-of-life care** locally and nationally at www.apmonline.org.
- 8 **Approach your hospital palliative care team** to find out about professional development opportunities in your trust or unit.
- 9 **Find advice and guidance on prescribing in palliative care** by registering free at www.palliativedrugs.com.
- 10 **Try out the free e-learning resource on end-of-life care** at www.e-elca.org.uk.

Appendix 2 Prompt tool for post-take ward rounds / general ward rounds

- Does the patient have an advance care plan?
- Does the patient have a valid and applicable advance decision to refuse treatment (ADRT)?
- Does the patient fall into one of the following categories?
 - advanced, progressive, incurable conditions(s)
 - general frailty and coexisting conditions that mean they may be expected to die within the next 12 months
 - existing condition(s) as a result of which they are at risk of dying from a sudden acute crisis
 - life-threatening acute condition caused by sudden catastrophic event(s).

If so, discuss preferences of treatment and place of care with the patient and their family.

Appendix 3 Prompt tool for mortality and morbidity meetings

- Was this death expected?
- Were the patient's priorities for end-of-life care (eg place of care/death) known?
 - If yes, were they adhered to?
 - If no, were there opportunities for advance care planning?
- Was the patient's terminal care supported by the integrated care pathway for the dying patient?
 - If not, should it have been?