

## We need to talk about Palliative Care

### General Medical Council

#### Our role

To set our response in context, I should say something about the role of the General Medical Council (GMC). We are an independent organisation that helps to protect patients and improve medical education and practice across the UK. In essence we:

- decide which doctors are qualified to work here and we oversee UK medical education and training.
- set the standards that doctors need to follow, and make sure that they continue to meet these standards throughout their careers.
- take action to prevent a doctor from putting the safety of patients, or the public's confidence in doctors, at risk.

Every patient should receive a high standard of care. Our role is to help achieve that by working closely with doctors, their employers and patients, to make sure that the trust patients have in their doctors is fully justified.

We are independent of government and the medical profession and accountable to the UK Parliament. Our powers are given to us by Parliament through the Medical Act 1983.

In offering views, we have grouped together your questions where we think that helps to keep our comment concise and focused on the underlying concerns.

**Q1. What has been your experience in terms of access to palliative and end of life care?**

**Q5. What works well in discussing palliative and end of life care and how is good practise communicated? Where do the challenges remain?**

#### *Our experience and support to doctors*

Supporting doctors to provide high standards of palliative and end of life care has been a priority area for the GMC since 2010 when we published our [guidance](#) '*Treatment and care towards the end of life: good practice in decision making*' (2010)\*. We published this guidance (an updated and expanded version of earlier advice to doctors) in response to feedback from doctors and the public about the issues that they find most challenging to

\* [http://www.gmc-uk.org/static/documents/content/Treatment\\_and\\_care\\_towards\\_the\\_end\\_of\\_life\\_-\\_English\\_0914.pdf](http://www.gmc-uk.org/static/documents/content/Treatment_and_care_towards_the_end_of_life_-_English_0914.pdf)

tackle when a patient is coming towards the end of life. (Annex A includes key aspects of our end of life care guidance which we think will be of most relevance to the Committee's work.)

As a support to doctors, our guidance provides a fairly comprehensive framework for ethical practice reflecting the legal requirements in Scotland and the rest of the UK and expected standards of good practice. It sets out how we expect doctors to work in partnership with patients and their families, the multi-disciplinary team and others across health and care services to meet the needs of individual patients. It places emphasis on effective communication with patients and their families; advance care planning; and attention to providing a good standard of clinical care which includes the provision of palliative care when appropriate and not just in the last days of a patient's life. Specifically in terms of palliative care, paragraphs 4, 22, 26-30 and 52 of our guidance are most relevant.

In the public consultation that underpinned our guidance, professionals and patients highlighted the challenges in accessing palliative and end of life care experienced by some groups of patients and the role doctors could play in addressing these issues.

We draw attention to this in paragraphs 8, 22-23 of the guidance. And we sign-post from the guidance to examples of external resources that may help doctors to more effectively meet the needs of disadvantaged patients and their families (in the 'references' section).

In addition, consultation feedback from doctors and other professionals flagged up the importance of ensuring that health and social care staff have a shared understanding of expected standards in this area, as a means of delivering a more consistent patient experience.

In response, we have sought to contribute to advice on good practice published by other organisations, to ensure a degree of alignment between professional standards. For example:

- we contributed to the development of the Scotland 'Do not attempt cardiopulmonary resuscitation' (DNACPR) policy framework.
- as a member of the Leadership Alliance for the Care of Dying People, we contributed to the development, in England, of the *Five priorities for care* which now form the basis for end of life care provided to all dying patients in England. This is a new approach to caring for people in the last few days and hours of life, that focuses explicitly on the needs and wishes of the dying person and those closest to them, including the importance of ensuring that their palliative care needs are met.

To help doctors navigate and work with our guidance, in their efforts to improve practice, we have published a range of resources that illustrate how the principles might apply to complex or challenging situations that arise in caring for people who are dying. In providing these additional resources, we

are responding to research evidence that doctors who have many demands on their time value support with difficult issues that is quick and easy to access and clearly relevant to the particular patients and circumstances that they encounter in their day to day work. (The research is published on our website [here](#).\*)

*Where do the challenges remain?*

Many of the challenges we were aware of in 2010 remain a focus of concern today. Doctors continue to need support to understand and address:

- the ethical and legal framework for end of life care especially in the face of emerging case law
- current expectations around good clinical practice, including the provision of specialist and generalist palliative care for a wider range of terminal conditions, and how to deliver this effectively within a complex and changing health and care system
- the potential communication barriers, including emotional and other distress that may arise, when decisions have to be made about treatment limitation and other aspects of care for a dying person.

In response, we have continued work to make our guidance more visible to doctors and patients, but with a greater focus on delivering resources that can help to make our guidance as practically helpful and widely accessible as possible. To this end:

- we have recently launched a continuing professional development (CPD) electronic application ('app') for all doctors to help them plan, carry out and evaluate their CPD which we will use to promote and enable them to access learning and development about palliative and end of life care. In doing so we will encourage them to think about how to use this information to improve standards of care for their patients. This winter we are launching an interactive decision-making tool to guide doctors through the steps involved in supporting patients who have impaired capacity or lack capacity to make a decision about treatment and care. Many of the case studies that illustrate steps in the decision-making process will focus on palliative and end of life care issues.
- we are developing a new dedicated section of our website that links together all our end of life care content and signposts the visitor to helpful external resources, to make relevant tools and guidance more easily identifiable and accessible to doctors and other users.

\* <http://www.gmc-uk.org/about/research/25040.asp>

- we are exploring the development of a partnership programme in England in which we hope to work with external organisations to deliver a programme of combined guidance, training and follow on support to groups of doctors who are seeking to improve the standards of end of life care delivered to their local population of patients.
- we are supporting NHS e-Learning for Healthcare in its work to update and promote e-learning content on palliative and end of life care.

**Q2. How could it be ensured that access to palliative and end of life care is equitable and available in all areas and for all types of terminal illnesses?**

**Q8. What training and support is provided to Health and Care staff on discussing Palliative Care with patients and families and are there any areas for improvement?**

We believe that a key factor in improving the availability of and access to palliative and end of life care is the supply of trained and experienced staff to facilitate the expansion of services. An important means of increasing the supply of such staff is to ensure that non-specialist doctors, doctors in the early years of training and medical students in their clinical placements, are being supported to develop their knowledge and skills in this area, including their competence and confidence around discussing palliative and end of life care needs with patients and their families.

To this end we have been working with other organisations on initiatives that increase opportunities for education and training and CPD related to end of life care. And we are delivering local engagement events with a strong educational content, through our liaison staff.

*Working with others to deliver resources that improve knowledge and understanding*

We have been working closely with a number of stakeholders on initiatives to improve doctors' knowledge and understanding of current good practice in delivering palliative and end of life care. To illustrate, in Scotland we:

- are a partner in the newly set up NHS Education for Scotland Bereavement Hub with representation across steering, training and advisory groups. We supported the setting up of the website including contributing content and promoting it through our communication links to doctors in Scotland ([www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk)). We actively supported the Scottish government's development and dissemination of guidance on the new Medical Certification of Death process in Scotland (which came into force on the 13 May 2015) including the circulation of a leaflet advising doctors of our support for the new guidance. As the project develops we will be working with NES to develop input to training and create further links between both

organisations' resources covering the broader issues relating to end of life care, in particular communication and decision support tools. As part of this we have been developing plans with NHS Education for Scotland to run a series of workshops for doctors across the Scottish health board areas during 2015.

- are feeding in to the review of the Scotland 'Do not attempt cardiopulmonary resuscitation' (DNACPR) policy framework and educational materials.

In the other countries we are:

- exploring opportunities to work with Marie Curie on its 'Transforming your palliative and end of life care' programme in Northern Ireland and supported a pilot training event in March 2015 for GPs and district nurses. Marie Curie are reflecting on how to develop this work further and we will be meeting to discuss how we can work with them as this is rolled out.
- working with RCGP Wales to develop a training DVD for GPs. The content is focused on highlighting the importance of advance care planning in primary care, explaining the difference that having conversations with patients at the right time can make, signposting some helpful sources of information and bringing a range of perspectives to the issue – some from doctors and some from patients and their families. This work is due to be completed in autumn 2015 followed by a campaign to promote uptake and use of the DVD. The DVD will be sent to all GP practices in Wales and hosted on our website.
- working with the National Council for Palliative Care (NCPC) to explore the possibility of producing some short films (during 2015) to help doctors with the difficult communication challenges such as broaching discussions about dying; questions about treatment limitation; and consideration of the circumstances in which palliative care may be appropriate. It is expected that any films produced will be available early in 2016 and will contribute to the NCPC's work through the Dying Matters Coalition.

**Q3. Can you identify any areas in terms of access to palliative and end of life care that should be focused on as priorities?**

*Enhancing curricula and medical education and training*

As a longer term measure, we believe a strong focus on education and training is essential. We are working with education and training providers and commissioners to look at ways in which we can enhance the curriculum content and teaching about end of life care, at undergraduate and postgraduate level.

Together with the Medical Schools Council, we wrote to all Deans of medical schools last summer reminding them of the need to ensure that the curricula

they set equip undergraduate students effectively to support the care of dying people. The letter to medical schools was followed up with a question about end of life care in the annual return we require medical schools to complete as part of the quality assurance process. The resulting data by schools in Scotland (please see Annex B) provides a broad overview of coverage of palliative and end of life care.

Working with medical schools, postgraduate training bodies, and local education providers, we will develop case studies for publication on our website, based on current examples of good practice in teaching and learning about end of life care.

We are consulting jointly with the Academy of Medical Royal Colleges on a draft framework for 'generic professional capabilities'. Designed to strengthen the curricula we approve for postgraduate specialty training, the framework will focus on areas of professionalism such as shared decision making, effective communication and team working and humane interventions like nutrition and hydration. These areas are common to many medical specialties, integral to all clinical care, and particularly important to palliative and end of life care. The [consultation](#)\* runs until 22 September 2015.

#### *Wider engagement to raise awareness*

We would highlight that we have experienced strong and continuing demand for us to deliver promotion of our guidance on palliative and end of life care.

We are frequently asked to run discussion sessions on this important issue and have developed a training package which focuses on the areas of our guidance covered at Annex A. Our teams regularly meet with and run sessions for groups of doctors, medical students and patients, clinical commissioning groups (in England) and other organisations involved in local healthcare services. (Our Regional Liaison Service in England received 108 requests from doctors in 2014). From Autumn 2015 we will have a dedicated Liaison Adviser in our Scottish office and supporting this work across Scotland will form part of their role.

We are keen to support work in Scotland through collaborations and using our regulatory reach to add value where we can, for example we are currently a member of the National Advisory Group on Palliative and End of Life Care Stakeholder Group in Scotland which is feeding into the development of the new Strategic Framework for Action.

We would be happy to meet with members of the Committee to discuss the issues further. And we certainly remain open to suggestions on how we might better support doctors in Scotland to improve standards in this area.

### **General Medical Council**

\* <http://www.gmc-uk.org/education/23581.asp>

## Annex A: GMC Guidance

Our standards define what makes a good doctor by setting out the professional values, knowledge, skills and behaviours required of all doctors working in the UK. We consult with a wide range of people, including patients, doctors, employers and educators to develop our standards and guidance.

The core professional standards expected of all doctors are set out in Good medical practice which covers fundamental aspects of a doctor's role, including working in partnership with patients and treating them with respect. We provide detailed guidance on ethical principles that most doctors will use every day, such as consent and confidentiality, and specific guidance on a range of areas such as raising concerns about patient safety, doctors' child protection responsibilities, and providing care for people who are dying. We also develop case scenarios and tools that help doctors apply the principles in their practice.

Serious or persistent failure to follow our guidance will put a doctor's registration at risk.

### Treatment and care towards the end of life: good practice in decision making

The following paragraphs of this explanatory guidance may be particularly relevant:

#### Role of relatives, partners and others close to the patient

- 17** The people close to a patient can play a significant role in ensuring that the patient receives high-quality care as they near the end of life, in both community and hospital settings. Many parents, other close relatives and partners, as well as paid and unpaid carers, will be involved in discussing issues with a patient, enabling them to make choices, supporting them to communicate their wishes, or participating directly in their treatment and care. In some cases, they may have been granted legal power by the patient, or the court, to make healthcare decisions when the patient lacks capacity to make their own choices.
- 18** It is important that you and other members of the healthcare team acknowledge the role and responsibilities of people close to the patient. You should make sure, as far as possible, that their needs for support are met and their feelings respected, although the focus of care must remain on the patient.
- 19** Those close to a patient may want or need information about the patient's diagnosis and about the likely progression of the condition or disease, in order to help them provide care and recognise and respond to changes in the patient's condition. If a patient has capacity to make decisions, you should check that they agree to you sharing this information. If a patient lacks capacity to make a decision about sharing information, it is reasonable to assume that, unless they indicate

otherwise, they would want those closest to them to be kept informed of relevant information about their general condition and prognosis. (There is more guidance in our booklet on Confidentiality.) You should check whether a patient has nominated someone close to them to be kept informed and consulted about their treatment.

- 20** When providing information, you must do your best to explain clinical issues in a way the person can understand, and approach difficult or potentially distressing issues about the patient's prognosis and care with tact and sensitivity. (See paragraphs 33-36 on addressing emotional difficulties and possible sources of support.)
- 21** When discussing the issues with people who do not have legal authority to make decisions on behalf of a patient who lacks capacity, you should make it clear that their role is to advise the healthcare team about the patient's known or likely wishes, preferences, feelings, beliefs and values. You must not give them the impression they are being asked to make the decision.

### **Advance care planning**

#### *The benefits*

- 50** As treatment and care towards the end of life are delivered by multidisciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs.
- 51** The emotional distress and other pressures inherent in situations in which patients are approaching the end of their life sometimes lead to misunderstandings and conflict between doctors and patients and those close to them, or between members of the healthcare team. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the patient's care.

#### *What to discuss*

- 52** Patients whose death from their current condition is a foreseeable possibility are likely to want the opportunity (whether they are in a community or hospital setting) to decide what arrangements should be made to manage the final stages of their illness. This could include having access to palliative care, and attending to any personal and other matters that they consider important towards the end of their life.
- 53** If a patient in your care has a condition that will impair their capacity as it progresses, or is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility, you should encourage them to think about what they might want for themselves should this happen, and to discuss their wishes and concerns with you and the healthcare team. Your discussions should cover:

- a** the patient's wishes, preferences or fears in relation to their future treatment and care
  - b** the feelings, beliefs or values that may be influencing the patient's preferences and decisions
  - c** the family members, others close to the patient or any legal proxies that the patient would like to be involved in decisions about their care
  - d** interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation (CPR), when it may be helpful to make decisions in advance
  - e** the patient's preferred place of care (and how this may affect the treatment options available)
  - f** the patient's needs for religious, spiritual or other personal support.
- 54** Depending on the patient's circumstances, it may also be appropriate to create opportunities for them to talk about what they want to happen after they die. Some patients will want to discuss their wishes in relation to the handling of their body, and their beliefs or values about organ or tissue donation.
- 55** You must approach all such discussions sensitively. If you are unsure how best to do this or how to respond to any non-clinical issues raised by the patient, you should refer to relevant guidelines on good practice in advance care planning. If the patient agrees, you should involve in the discussions other members of the healthcare team, people who are close to the patient, or an independent advocate.

*What patients do not want to know*

- 56** Some patients may not be ready to think about their future care, or may find the prospect of doing so too distressing. However, no-one else can make a decision on behalf of an adult who has capacity. If a patient asks you to make decisions on their behalf or wants to leave decisions to a relative, partner or friend, you should explain that it is important that they understand the options open to them, and what the treatment will involve. If they do not want this information, you should try to find out why.
- 57** If the patient still does not want to know in detail about their condition or the treatment, you should respect their wishes as far as possible. But you must explain the importance of providing at least the basic information they need in order to give valid consent to a proposed investigation or treatment. This is likely to include what the investigation or treatment aims to achieve and what it will involve. For example, whether a procedure is invasive; what level of pain or discomfort they might experience and what can be done to minimise it; what they should do to prepare for the investigation or treatment; and whether it involves any serious risks.

- 58** If the patient insists that they do not want even this basic information, you must explain the potential consequences of carrying out an investigation or treatment if their consent may be open to subsequent legal challenge. You must record the fact that the patient has declined relevant information and who they asked to make the decision about treatment. You must also make it clear that they can change their mind and have more information at any time.

*When others want information to be withheld from the patient*

- 59** Apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment. If you withhold information from the patient, you must record your reasons for doing so in the medical records, and be prepared to explain and justify your decision. You should regularly review your decision and consider whether you could give information to the patient later, without causing them serious harm.

*Formalising a patient's wishes*

- 60** If a patient wants to nominate someone to make decisions on their behalf if they lose capacity, or if they want to make an advance refusal of a particular treatment, you should explain that there may be ways to formalise these wishes, such as appointing an attorney or making a written advance decision or directive. You should support a patient who has decided to take these steps. You should provide advice on the clinical issues and recommend that they get independent advice on how to formalise their wishes.

*Recording and sharing the advance care plan*

- 61** You must make a record of the discussion and of the decisions made. You should make sure that a record of the advance care plan is made available to the patient, and is shared with others involved in their care (provided that the patient agrees), so that everyone is clear about what has been agreed. (See also paragraphs 22-23 about working in teams and across service boundaries.) If a patient makes an advance refusal of treatment, you should encourage them to share this information with those close to them, with other doctors, and with key health and social care staff involved in their care.
- 62** You must bear in mind that advance care plans need to be reviewed and updated as the patient's situation or views change.

## Annex B: End of Life Care MSAR Published Responses

Medical schools in the UK were asked the following question:

“Paragraph 14J of TD09, which covers the doctor as a practitioner and includes outcome requirements on the diagnosis and management of clinical presentations, requires that students must: · Contribute to the care of patients and their families at the end of life, including management of symptoms, practical issues of law and certification, and effective communication and team working. The care of dying people is an important issue, and it is key that students are prepared effectively. We would like to know how you have reflected on and made changes as a result of the Leadership alliance on the Care of Dying People report.

How does your school teach students how to best handle the issue of the care of dying people?”

The responses of the Scottish medical schools were as follows:

### Aberdeen

[Information redacted] has had a central part in the development of learning outcomes for medical students and foundation doctors throughout Scotland. A national group developed consensus learning outcomes and provided a forum for discussion, sharing of best practice and educational and assessment resources and mutual support for advocacy of palliative care teaching in the medical schools. [Information redacted] Within our core curriculum the following relevant formal teaching and learning opportunities spiral through the course:

Year 1&2: during the Foundations of Primary Care programme that spirals through Years 1 – 3, students introduced to patients with life-limiting illness, palliation and dying mentioned.

Year 3: Ethics system. Half day devoted to end-of-life decision making including Abortion and euthanasia debates.

Year 4: one week of Palliative Medicine. During this week students meet patients in a hospice setting attend and present at multi-disciplinary team meetings, spend time visiting patients in the community with the Macmillan nurses, visiting patients in the acute hospital setting with the HSPCT, and meeting patients in the palliative care day unit. Students watch video about end of life care and have facilitated discussions with consultants in palliative care.

Year 5: 2 days ‘End of Life’ teaching in the Professional Practice Blocks (PPB) – one at the beginning of final year and one at the end of final year: Over these two sessions the students will meet with [information redacted]. A number of DVD clips relating to end of life are used to prompt group discussion. We also use a national teaching DVD resource on DNACPR. We speak about the importance of accurate documentation and the related legal

issues. We highlight the essential need for good communication with patients and their families during this time and to give them the support they need. There are small group sessions on both death certification and symptom control.

In addition in both Year 4 and 5 clinical placements there are many opportunities for students to encounter end of life learning opportunities. Many medical wards have regular quality improvement meetings where all deaths are discussed; students are actively encouraged to witness death certification during clinical blocks and to visit the mortuary. We always speak about end of life and cardiac arrests during medical block feedback and we share and reflect on a variety of situations. During the introductory session to Final Year we highlight the emotional issues there can be for students and professionals in dealing with end of life issues. We emphasise the pastoral support available from academic staff, student support and regents.

## Dundee

The Leadership Alliance on the Care of Dying People report relates specifically to the NHS in England and has been adopted by NHS England following the withdrawal of the Liverpool Care Pathway (LCP). While we are aware of this in Scotland, separate guidance has been given following the withdrawal of the LCO and this can be found in the interim guidance from the Scottish Government on Caring for people in the last stages of life. It is likely that a strategic framework will be developed by 2015 and it may well be that we will change our teaching to relate to this. Currently, the concept of caring for dying people is taught across the years in palliative medicine teaching. It is covered from year 1 through many of the speciality teaching blocks and during aging teaching in year 3 there is a particular emphasis on end-of-life care. During the transition block in year 4 advanced care planning, anticipatory prescribing and end-of-life care is covered. Additional experience is provided through the palliative care team in the hospital and hospice setting. During all teaching the physical, psychological, social and spiritual aspects of care are considered for both the patient and their carers. All learning outcomes are mapped to tomorrow's Doctors outcomes.

## Edinburgh

Care of dying people is addressed in:

- Specific clinical experience with palliative care specialists in Y4 Oncology and Y5 Medicine of the Elderly modules.
- Other clinical experience in any Y3-5 attachments but particularly Y4 and Y5 GP, and Y5 Emergency Medicine and Medicine. It appears to a significant extent also in cardiology, renal medicine, neurology, respiratory medicine, and latterly into neonatology.
- There is relevant teaching in Year 1 in the Health Ethics and Society module and in pharmacology lectures addressing for example pain and vomiting in Years 1 and 2.

- Clinical Communication Workshops in Y3 and Y4 (particularly the latter on breaking bad news). The underlying principles guiding this teaching are that:
- Palliative care is relevant to many specialties and is best integrated into these relevant modules.
- Palliative care is broader than end of life care and that end of life care is made more difficult if supportive and palliative care, earlier in the patient's illness have been poor.
- The principles of symptom control can be taught easily. However, underpinning the appropriate use of this knowledge are the challenging areas of communication, empathy, working with families and the multidisciplinary team.
- Checklists in pathways are not used in our teaching; rather, the students are taught the importance of assessing each individual and his/her wider situation. Any management and action plans have to be individualised and reassessed on the basis of individual needs. There is no predetermined pathway for an individual, rather guiding principles on assessment and management.

### Glasgow

Year 1: There is a visit to a hospice as part of Vocational Studies In addition there is a session titled "Utility v Futility" (under Right Thing to Do)

Year 2: In Vocational Studies in this year there is a session including "Value of Life" and patients seeking assistance to end their lives.

Year 4/5: 2 day hospice placements delivered by palliative medicine (occurs during Years 4/5 General Practice visit block) Year5 There is an session during the Preparation for Practice academic week on communication around death and dying (delivered jointly between Communication Skills and Palliative Medicine)

### St Andrews

Students are given 2 lectures on end of care – one in year 2 and one in year 3. The first of these introduces them to the role and aims of palliative care, focusing on anticipatory care and discussing existing guidance promoting the delivery of high quality end of life care. This lecture discusses the GMC document 'Treatment and Care towards the End of Life' and specifically mentions the 'One Chance to Get it Right' document and the 5 key priorities it highlights. This sits alongside ethics teaching during which students discuss issues surrounding Advance Statements and Advance Decisions to Refuse Treatment. The lecture in year 3 reinforces teaching from the previous year, but focuses more specifically on principles of pain management in a palliative care setting. This teaching is blueprinted and assessed in the main assessments in each appropriate year.