

To consider

End of Life Care: Consultation

Issue

1. This paper invites Council to consider the draft guidance on end of life care and the plans for consultation.

Recommendations

2.

a. To endorse the draft guidance (Annex B) as the basis for consultation (paragraphs 9-27).

b. To authorise the Chair of the Council and the Convenor of the Standards and Ethics Reference Group to approve any necessary amendments to the consultation draft (paragraph 28).

c. To endorse the proposals for the consultation (paragraphs 29-42).

Further information

3. If you require further information about this paper, please contact us by email: gmc@gmc-uk.org or tel. 0161 923 6602

Background

4. Our guidance *Withholding and Withdrawing Life-Prolonging Treatments* was published in 2002. The guidance was developed following a number of fitness to practise cases. The purpose of the guidance was to help doctors in decision-making and to clarify what we regarded as acceptable practice in this difficult area.

5. Since 2002, there have been developments in the legal and ethical framework within which end of life care is provided. They include:

a. Case law – the 2005 Court of Appeal judgment, in *Burke v GMC*, made clear that doctors are not required to provide artificial nutrition and hydration or other treatment in circumstances where they provide no clinical benefit or are not in a patient's best interests. Other judgments have explored issues such as the validity of advance refusals of treatment; the factors to be considered in decisions about whether to stop, or not to offer, potentially life-prolonging treatments to very sick children; and how the European Convention on Human Rights impacts on medical decisions.

b. Legislation - the Mental Capacity Act 2005 (England and Wales) has established a framework for making decisions about medical care and treatment for individuals who are unable to decide for themselves. More information has become available about how the earlier Adults with Incapacity (Scotland) Act 2000 works in practice.

c. Research has increased understanding of the effects of treatments that may be given in end of life care. For example, research has provided new evidence about the risks and benefits of clinically assisted nutrition and hydration for patients with advanced dementia.

d. Public policy – Government across the UK has placed greater importance on improving the availability and quality of end of life care for all patients, including ensuring that the needs of more vulnerable groups are specifically addressed.

6. Our guidance on *Consent: Patients and doctors making decisions together* (published June 2007) set out broad principles for good medical decision-making. They apply in a broad range of situations, including decisions about end of life care. The former Standards and Ethics Committee agreed that *Consent etc* should be supplemented by more detailed advice about end of life decisions.

7. A comprehensive review of *Withholding and Withdrawing Life-Prolonging Treatments* was launched in September 2007. A working group, chaired by Lady Eames, oversaw the review. The members (Annex A) come from around the UK and represent a wide variety of interests including medicine and nursing, patient and carer organisations, and faith groups.

8. The review began with a scoping exercise, which included a short written consultation. In response to the views we received, we agreed that, rather than continuing to focus on withholding and withdrawing treatments, the new guidance should take a broader approach, addressing the principles that should inform good care for patients nearing the end of life, and doctors' responsibilities for the patient and those close to them after they have died.

Discussion

9. The consultation draft developed by the Working Group, *End of Life Treatment and Care: Good Practice in Decision-Making*, is at Annex B. This builds on our existing guidance on good decision-making, and contains additional advice on situations that doctors find challenging, as well as issues that cause concern to patients and their carers.

Advance care planning (paragraphs 42-60)

10. This section has been significantly expanded from the advice in *Withholding and Withdrawing Life-prolonging Treatments*, taking account of recommendations in the End of Life Care Strategy in England and the National Action Plan in Scotland.

11. The section provides information on the benefits of holding early discussions about future care, with patients and those close to them; offers detailed advice on how to approach such discussions; highlights the possibility of formalising the patient's wishes into an advance statement or advance refusal of treatment; and offers advice on how to act on such requests and refusals at a later stage.

Clinically assisted nutrition and hydration (paragraphs 82-96)

12. The term 'clinically assisted' has been used in place of the more usual 'artificial' to provide a more accurate description of the use of tubes and cannulas to provide nutrition and hydration that should be clear to all readers.

13. The provision of clinically assisted nutrition and hydration was the most contentious issue arising from *Withholding and Withdrawing Life-Prolonging Treatments*, and the guidance on this point was at the heart of the judicial review brought by Leslie Burke in 2004. This case addressed whether patients had a right to receive clinically assisted nutrition and hydration up to the point of death, if that was their choice, irrespective of doctors' views of the benefits of such treatment, or its risks or side-effects.

14. The debate in the media that surrounded the case showed that some members of the public had similar concerns about the treatment of vulnerable patients, and were fearful that they would not receive clinically assisted nutrition and hydration that was necessary to prolong their lives. To address those concerns, the draft guidance includes advice about:

- a. How to address the clinical complexities in assessing and meeting the nutrition and hydration needs of patients who are nearing the end of life.

- b. What is legally and ethically permissible when considering the possibility of withdrawing or withholding clinically assisted nutrition or hydration.
- c. How doctors should deal with requests for treatments to which the patient attaches special importance, when those treatments are unlikely to offer any overall benefit.

15. Paragraphs 89-92 of the draft are particularly important, as they deal with various circumstances in which withdrawing clinically assisted nutrition or hydration may be considered. In particular, paragraph 90 includes advice that clinically assisted nutrition and hydration may be withdrawn from a patient who lacks capacity, where death is not imminent, if provision of the treatment would be 'intolerable in all the circumstances'. This is a substantial change from the existing guidance, and goes some way to meeting the 'intolerability test' proposed by the Disability Rights Commission and other bodies in the Burke case.

16. Paragraph 92 deals with situations where patients who lack competence have previously expressed a wish to receive nutrition and hydration up to the point of their death. In relation to those cases, we advise that, in considering the overall benefits and harms of providing treatment, acting against the patient's wishes should be deemed to be causing harm.

Cardiopulmonary resuscitation (paragraphs 97-110)

17. Some doctors have criticised the advice on CPR, in *Withholding and Withdrawing Life-prolonging Treatments*. They have argued that it lacks clarity on when CPR will be 'futile' or may not be in a patient's best interests and that this has led to differences in understanding and practice in different areas of practice (palliative care, geriatrics, intensive care) and different settings (palliative care at home or in a hospital).

18. The guidance on consulting patients and their families was also open to different interpretation about when, and to what extent, patients or those close to them should be consulted or informed about 'do not attempt resuscitation' decisions. It was argued that the guidance did not allow for flexibility of approach, and could lead to doctors feeling compelled to seek views from patients when a clear clinical decision had been taken not to provide CPR.

19. A further concern was that the guidance gave no definitive advice on whether doctors should attempt CPR requested by a patient with capacity, where it would have very little chance of success.

20. The debate about involving patients and those close to them in discussions has been overtaken by capacity legislation which reinforces the expectation that, where there is a balancing of benefits with burdens, risk or other factors, the patient's wishes and preferences must be taken into account, by helping the patient to decide (to the extent that they are willing and able to do so) or by involving the patient's proxy decision-makers and carers.

21. The concerns about attempting CPR with a low chance of success, where a patient with capacity requests it, have been clarified to some extent by the Court of Appeal judgment in *Burke v GMC*.

22. In 2007, the BMA, the Royal College of Nursing and the Resuscitation Council (UK) published joint guidelines on decisions relating to CPR. The guidelines give a clear explanation of the clinical complexities and provide comprehensive advice about the circumstances where:

a. It is not necessary or appropriate to initiate a discussion with a patient but may be appropriate to inform them, their carers and those close to them.

b. It is important to provide the opportunity for patients to discuss CPR if they wish to do so, with a view to reaching agreement about whether it should be attempted.

c. It is necessary and appropriate to consult those close to the patient about whether CPR should be attempted.

23. We participated in the development of the joint guidelines and the former Standards and Ethics Committee, and the Council, expressed their support for the terms of the published document. The Working Group agreed to include similar advice in the draft *End of Life Care* text.

Resource constraints (paragraphs 33-35)

24. This new section more clearly acknowledges the challenges faced by doctors when treatment decisions are complicated by resource constraints: this is particularly relevant to doctors working in intensive care, who often have more patients than beds available in intensive care units

25. The section seeks to provide a framework of key points that doctors should take into account, to ensure that they address the full range of ethical issues in any given situation. It reflects the Working Group's view that, ideally, such decisions should be made in accordance with an agreed national or local policy rather than on a case by case basis.

Care after death (paragraphs 67-71)

26. This new section makes clear that a doctor's responsibility does not end when a patient dies. It covers a range of concerns that have been raised with us in recent years, including dignity and respect for the body, responsibilities towards families, carers and others close to the patient (including taking account of cultural and religious considerations) and death certification.

27. The section also addresses organ donation, encouraging doctors to raise the issue in appropriate circumstances, which should contribute to current initiatives to increase the numbers of organ donors. The draft does not provide detailed guidance, which is provided by a number of other medical organisations. We will include references and links to such guidance.

Recommendation: To endorse the draft guidance as the basis for consultation.

28. The draft will be reviewed and revised following the Council meeting to take account of members' comments and suggestions.

Recommendation: To authorise the Chair of the Council and the Convenor of the Standards and Ethics Reference Group to approve any necessary amendments to the consultation draft.

29. We will invite preliminary comments from the Word Centre, to establish whether any of the language in the draft is likely to cause difficulties when we apply for plain English accreditation for the final version.

Consultation proposals

30. We plan to start a wide ranging consultation on the draft guidance in the week commencing 23 March 2009. The consultation will last for four months, finishing in mid-July 2009.

Aims

31. Our primary aims for the consultation are to:

a. Test that the new draft guidance contains principles and standards that are: clear; relevant; achievable within the different environments in which doctors practise; provide an accurate reflection of the legal position; promote best practice; and take account of equality, diversity and human rights considerations.

b. Provide sufficient and appropriate opportunities for key interest groups to inform the decisions about content.

32. Our secondary aims are to raise awareness and understanding of:

a. The purpose of GMC guidance and its role in improving practice.

b. The specific challenges presented by the issues being consulted on.

c. The robustness and openness of our process for developing guidance.

Key interest groups

33. To meet our objectives we must provide sufficient and appropriate opportunities for our key interest groups (Annex C) to comment and inform the content of the final guidance. The consultation process will therefore need to involve a number of different approaches to provide appropriate means for different groups to participate. They will include a written consultation, a national conference and other events in the four UK countries targeting specific issues and groups.

34. The consultation will be conducted in line with our Consultation Protocol.

Written consultation

35. The written consultation will seek views on a series of questions about the drafting and the principles that underpin it. All the documents, including the new draft and existing guidance, will be available on-line, and we will encourage respondents to use the on-line form to send us their comments. Organisations and individuals in Wales will receive the letter in both English and Welsh.

36. In addition to the main consultation document, we will also produce a short questionnaire, targeted primarily at individual doctors, patients, carers and members of the public which will ask some more general questions about the key issues in end of life care but which do not require respondents to have a detailed knowledge of the draft guidance.

National conference

37. We will hold a national consultative conference during the consultation period. We are still in the process of finalising the programme and dates for the conference but it is likely to be held in early June 2009 in central London. An invited audience of 200 delegates from a wide range of backgrounds will discuss the key issues and challenges in end of life decision-making and will also have the opportunity, in workshop sessions, to comment in more detail on specific aspects of the draft guidance.

Other meetings and events

38. We will also hold a series of events throughout the UK to provide further opportunities for our key interest groups to be involved in the consultation. These meetings will include some general 'roundtable' meetings as well as some smaller, more focused meetings to explore issues most relevant to particular groups, such as older people, disability rights groups, ethnic minority groups and individual doctors.

Patient and carer views

39. One of our main challenges is finding ways to hear the views of those most directly affected by the issues in the guidance - patients with terminal or life limiting conditions, their carers and family members, including those who are recently bereaved.

40. Throughout the consultation period, we will raise awareness of the consultation with organisations that provide support and services to patients and carers and encourage them to respond to the consultation. The ability to complete the short questionnaire rather than the more detailed written consultation may help encourage responses.

41. However, we understand that the individuals most affected by the guidance may not wish, or may not be in a position, to respond in this way. We have invited Healthtalkonline (formerly called DIPEX) to undertake secondary research. Healthtalkonline has created a database of patient experiences through in-depth qualitative research into over 40 different illnesses and health conditions. They have agreed to undertake secondary analysis of a number of the interviews they have conducted with patients and carers in projects on Living with Dying, cancer and Motor Neurone Disease. The analysis will identify common concerns, wishes and problems about end of life care which were raised by the interviewees. An initial review of their database suggests they will have about 130 interviews which can be included in the study.

42. The report will allow us to consider the stories and views of a large number of patients and carers who have been directly affected by the issues covered in the guidance.

Recommendation: To endorse the proposals for the consultation.

Resource implications

43. The costs of developing the guidance have been included in the budgets for Standards and Ethics Team and the Communications Directorate. The working group meetings in 2009 will cost about £11,000. The consultation, including the conference, meetings across the UK and Healthtalkonline research, will cost about £45,500. The print costs are estimated at £60,000 with an additional £15,000 for overseas postage. Copies of the booklet are sent to doctors with *GMC Today* and are not budgeted separately.

Equality

44. Equality, diversity and human rights issues are key considerations as we develop our proposals for guidance on end of life care and treatment. The Equality Impact Assessment for the review of the original *Withholding and Withdrawing Life-prolonging treatments* guidance started in September 2007 and will continue through the development of the new *End of Life* guidance.