General Medical Council

Regulating doctors
Ensuring good medical practice

To consider

Guidance on *Treatment and Care towards the End of Life: Good Practice in Decision Making*

Issue

1. The publication, launch and promotion of the new guidance *Treatment and Care towards the End of Life: Good Practice in Decision Making*.

Recommendations

2.

a. To approve the guidance for publication (paragraphs 8-17 and Annexes A and B).

b. To note the plans for launching the guidance (paragraphs 18-23).

c. To note the plans for longer term implementation of the guidance (paragraphs 24-26).

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. Strategic Aim Four of the Business Plan 2010 is 'To provide doctors with relevant up-to-date guidance on professional standards and ethics'. Publication of the guidance *Treatment and Care towards the End of Life: Good Practice in Decision Making* will fulfil one of the commitments we made to meet this aim.

5. The guidance (Annex A) has been developed following a comprehensive review of our booklet *Withholding and Withdrawing Life-Prolonging Treatments* (2002). A working group, chaired by Lady Christine Eames, was convened in February 2008 to lead the review. The members came from around the UK and represented a wide variety of interests including medicine and nursing, patient and carer organisations, and faith groups. An initial scoping exercise identified a number of reasons for reviewing the guidance, bringing it into line with current common and statute law and broadening its scope to cover good practice in providing treatment and care for patients approaching the end of life. A summary of the findings of the scoping exercise are set out in paragraph 1 of Annex B.

6. Between February 2008 and February 2010 the Working Group developed the draft and oversaw a four month public consultation that engaged all our key interest groups and included consultation events in the four UK countries. The Group considered more than 130 recommendations for amending the draft guidance to reflect feedback from the consultation. Council members were kept informed of progress, and the new guidance takes account of Council's views on a number of key issues, as well as advice from leading Counsel about compatibility with the different legal frameworks in the UK jurisdictions. There are no outstanding policy issues to be decided.

7. The final version of the guidance (Annex A) includes changes proposed by Council members in informal session on 31 March 2010. It has been reviewed by Ms Ros Levenson, Dr John Jenkins and Professor Terence Stephenson and approved for publication by the Chair of Council.

Discussion

Principles underpinning the guidance

8. The guidance seeks to support doctors in delivering high quality care to all patients, by providing an up to date framework for decision making. In drafting the guidance, the Working Group first identified the key principles that form the basis of good care for patients nearing the end of life. These were:

a. Respect for equality and human rights.

b. Presumption in favour of prolonging life.

c. Presumption of capacity.

d. Maximising capacity to make decisions.

9. These principles are discussed in more detail in paragraphs 2-5 of Annex B.

Language and terminology in the guidance

10. The language and terminology used in the guidance has presented considerable challenges. This partly arises from the strength of feeling from some of our key interest groups on the content of the guidance, leading to equal feeling about the language and terminology used in the guidance. A second issue arose from the different language used in the legislation that applies in the UK jurisdictions. The GMC's guidance is addressed to all doctors in the UK, so it is vital that it does not appear to exclude doctors in some parts of the UK. The language used in the guidance needs to be both legally precise and (in places) clinically accurate. At the same time, it is clear that drafting in 'Plain English' is important if the guidance is to be of value to doctors and our other potential audiences, including patients and members of the public or those who advise them.

11. There were two particularly difficult issues in relation to terminology:

a. *Overall benefit – for patients who lack capacity to decide.* We have used 'overall benefit' to describe the ethical principle guiding decisions about the treatment and care of adults who lack capacity to make decisions. This term is not used in legislation, but is acceptable to Scottish Government and to the Department of Health (England). We are satisfied that where the guidance on overall benefit is applied with the decision making principles, it is consistent with the capacity legislation across the UK.

b. *Clinically assisted nutrition and hydration (replacing artificial nutrition and hydration).* The Working Group concluded from personal experience that the term 'artificial nutrition and hydration' to describe the provision of nutrition and hydration by tube or drip was misleading and even distressing to some patients and their families. The Group agreed to replace 'artificial' with 'clinically assisted', and raised a number of questions about this change in the consultation. The responses revealed a division in views between some organisations, including some representing doctors, who favoured the use of 'artificial', and individual doctors and patients who welcomed change. Council has considered the views expressed and the reasons for them, and has decided we should use 'clinically assisted' in this guidance.

Scope of the guidance

12. The guidance builds on the ethical principles which underpin our guidance *Consent: patients and doctors making decisions together* and expand and explain these in the context of providing good care towards the end of life.

13. The guidance provides decision making models which take a step by step approach to making decisions where patients have capacity and where patients lack capacity. The models take account of the statutory requirements introduced by the Adults with Incapacity (Scotland) Act and Mental Capacity Act. The models are referred to throughout the guidance to emphasise that the decision making principles remain the same at all stages of a patient's care, irrespective of the treatments involved.

14. The guidance covers new ground and expands the guidance on some difficult issues that were referred to briefly in the 2002 guidance. The guidance addresses a number of issues for the first time, including:

a. The role of relatives, partners and others close to the patient.

b. Advance care planning.

c. Advance requests for treatment.

d. Organ and tissue donation.

e. Care after death.

f. Decisions involving neonates and infants.

15. Paragraphs 6-14 of Annex B provide a description of the key points of the guidance on each of these issues.

16. The guidance also covers in more detail a number of areas of practice where applying the principles in the guidance can be complex. These include advance refusals of treatment, decisions about providing cardio-pulmonary resuscitation (CPR) and clinically assisted nutrition and hydration (CANH). Paragraphs 15-24 of Annex B provide a brief account of the main issues covered in these sections of the guidance.

17. Finally, the guidance includes a reference section giving examples of useful national resources available in the four UK countries; a legal annex highlighting relevant statute and case law; and a glossary of those terms that might be less familiar to some readers.

Recommendation: To approve the guidance for publication.

Publication and launch of the guidance

18. The guidance will be launched on the website immediately after approval by Council. Copies of the booklet will be sent to all doctors on the Register with *GMCtoday* in the week of 24 May 2010.

19. The Communications Directorate will be implementing an extensive communications programme to raise awareness and promote the guidance amongst doctors and our other key interest groups. This will include: a press launch and media campaign; launch events in England, Northern Ireland, Scotland and Wales; a Parliamentary briefing; promotion of the guidance at conferences and events; and briefing GMC staff on the new guidance.

Materials to support the new guidance

20. To coincide with the launch, we are publishing a small number of vignettes that illustrate how some of the principles in the guidance might apply in different cases. These vignettes will support a decision-making algorithm that guides people through the decision-making process, where questions arise about a patient's capacity to make their own decisions. In addition two longer case studies will be published that illustrate decisions about clinically assisted nutrition and hydration and CPR.

21. We will also publish on our website a report giving a detailed account of the development of the guidance, including the consultation and the changes to the guidance made as a result. It will also reference the Equality Impact Assessment (EQIA), the external audit of the consultation, and a list of the organisations that responded to the written consultation. These documents will also be published online.

22. A 'vodcast' has been produced which includes extracts from video interviews with a wide range of people who attended the public consultation in June 2009 and an overview of the contents of the new guidance. This will be used at launch events, and will also be available on our website.

23. We are developing an e-learning session jointly with the NHS E-Learning in End of Life Care for All (e-ELCA) programme. This is based on, and will refer to our guidance, and will be available to all doctors in the UK. We expect this session to be ready to go live soon after the launch of the guidance.

Recommendation: To note the plans for launching the guidance.

Longer term implementation plans

24. We are completing a plan for implementing the new guidance over the 6-12 months post-publication with support from an informal 'implementation group'. We have already made initial decisions that:

a. We will publish further case studies covering areas of the guidance not covered in the existing vignettes and case studies.

b. The next set of interactive Good Medical Practice in Action case studies, due to be launched in June 2010, will include two scenarios which explore issues in the new guidance.

c. When Bliss (the premature baby charity) publishes its leaflet to support parents making decisions about intensive care for their babies (May/June), as contributors to the new leaflet, we should explore the scope for collaboration in promoting awareness and use of the leaflet among the profession.

d. When the Scottish Government's new DNACPR policy is launched (in June), we should partner with them to promote our guidance alongside their policy which reflects our advice on DNACPR decision making.

25. There are a range of other ideas and proposals at various stages of development, including suggestions from organisations in Wales, Northern Ireland and Scotland. We are considering these in the wider context of our strategy and developing plans for implementation work across the range of GMC guidance. We are exploring the possibility of producing 'webinars' (online seminars) and using other online means of covering the issues raised by our guidance that doctors, medical schools and other key interest groups would like to explore.

26. We will also consider how we can make the guidance accessible to patients and the public. In the first instance we will discuss patients' and their families' needs with organisations such as Age UK, MND Association and other charities that provide support for patients approaching the end of life.

Recommendation: To note the plans for longer term implementation of the guidance.

Resource implications

27. The publication and distribution of the guidance is included in the budgets for Standards and Communications directorates, along with the costs of the putting together the 'vodcast', e-ELCA session and other materials to support the launch of the guidance.

Equality

28. Equality issues have been central to the guidance and have been explored throughout the development process. The Equality Impact Assessment is being published on our website as part of the 'story of the guidance'.

29. As part of our implementation plans we are considering where we can target the concerns and interests of groups within the diversity strands, the elderly, those with physical disabilities, people with learning disabilities, and members of black and ethnic minority communities, who we know experience particular problems in accessing and receiving good quality care towards the end of life.