To consider

Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision Making

Issue

1. Approval for publication as a consultation document of draft guidance on the considerations to be taken into account by doctors when deciding whether to withhold or withdraw life-prolonging treatment from a patient.

Recommendation

2. a. To consider the text of the draft guidance at Annex D (paragraph 35).

   b. To agree that the draft text should be issued for public consultation (paragraph 36).

Further information

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Background

4. The Standards Committee first considered whether the GMC should offer guidance on the difficult issues surrounding decisions to withhold or withdraw treatment in January 1998. The Royal College of Paediatrics and Child Health (RCPCH) had published guidance on *Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice* (preface and summary at Annex A), having consulted with representatives of patient groups and other interested parties. However, at that time there was little other published guidance on the subject from the Royal Colleges or professional bodies, and the Committee were not persuaded that a sufficiently wide consensus on good practice existed which could provide the basis for formulating GMC advice.

5. The Committee reviewed the position after the PCC, in April 1999, found Dr Ken Taylor guilty of serious professional misconduct in relation to the process by which he reached his decision to withdraw Fresubin (a liquid nutrition) from an elderly stroke patient. (A copy of the PCC’s finding is at Annex B.) The determination in Dr Taylor’s case was not intended to establish general principles for decisions about withdrawing or withholding life-prolonging treatment. However, the case was not reported accurately in the press, which led to many inquiries from concerned GPs and patients’ relatives about what some had perceived as new general requirements on doctors.

6. The Standards Committee agreed that advice on good practice should be prepared, not least to clarify the GMC’s position following the Taylor case. This coincided with the BMA’s publication in June 1999 of a detailed guidance booklet *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making* which had been prepared with extensive public consultation. (Reference copies are available from Standards Section.) Along with the earlier RCPCH document, this provided a reasonable body of opinion on which the Committee could draw to prepare advice. The Committee’s decision was reported to Council in November 1999 and July 2000.

7. A working group was set up in late 1999 to consider what form GMC guidance should take and prepare a draft text. Additional members were co-opted from outside the GMC with legal and other expertise – see the full list of members at Annex C. The Standards Committee meeting in September 2000 accepted their recommendations on a draft text – attached at Annex D. It was also agreed that, given the sensitivities surrounding withholding and withdrawing treatment, Council should be asked to approve a public consultation on the draft, to provide the opportunity for a wider audience to consider the scope, content and practicability of the proposed guidance.
Discussion

Overall presentation

8. It was originally intended to prepare a relatively brief guidance ‘statement’, framed around advice in Good Medical Practice and Seeking Patients’ Consent. However, providing guidance which clearly addresses the questions which doctors most frequently raise – see paragraph 4 of the text – requires a more thorough coverage of the issues. The draft guidance draws out the ethical and legal principles to be applied in this area of decision making, and builds these into a good practice framework that should ensure a properly considered decision is reached, in a way that respects patients’ rights and minimises the scope for later misunderstanding and dissent between those involved in the patient’s care. It also gives additional advice on how the guidance should be applied to decisions about cardiopulmonary resuscitation, an issue currently of great public concern.

Introduction

9. Paragraphs 1-3 are intended to make clear the main purpose of the guidance, and reassure readers that it is consistent with the law and does not support euthanasia or assisted suicide. Concern about our position on these points is likely to be the immediate focus of those who want to ensure that the current consensus (and legal prohibitions) against euthanasia and assisted suicide are not weakened.

Ethical and legal context

10. The bullet points in paragraph 4 identify the questions of general principle, and concern specific responsibilities for decision making, which are most frequently raised by doctors and other health care team members, patients and their families, and which we address in the rest of the guidance.

Ethical principles

11. Paragraph 5 encapsulates the ethical principles around which there is a well established consensus, and which allow for the possibility of withholding or withdrawing treatment in some cases. Readers who support a position which does not accept that life-prolonging treatment may be withheld or withdrawn are likely to have objections. However the wording of the last two sentences, with the phrases ‘…will usually be…’ and ‘…may be…’, should not imply that it is generally permissible to withhold or withdraw treatment, but rather that judgement must be exercised in individual cases. The rest of the guidance sets out the basis on which such judgements should be made.

Competent patients, and those who lack capacity to decide

12. Paragraphs 6-7 address the decision-making rights of competent adults and children, and who has responsibility for, or a role in, making decisions on behalf of incompetent patients. It is difficult to give only the ethical position in relation to children without direct reference to how the legal position constrains their rights. By cross referencing to our existing guidance on children and consent – reproduced in
Appendix A of the document - it is possible to keep the text relatively short. One of the questions for the consultation exercise could be whether it is more helpful to move all the references to children into a separate section.

**Differences of view about best interests**

13. Paragraph 8 addresses the difficult circumstances where, for example, family members have opposing views about what would be best for a patient, or the patient’s partner or a health care team member disagrees with the doctor’s view about what would be in the patient’s best interests. The advice here, along with that in paragraph 33 of the good practice framework, is intended to help minimise any conflict and ensure that appropriate steps are taken to reach a resolution.

14. It was suggested in Committee that consideration be given to the position of a doctor who has a conscientious objection to withdrawing a life-prolonging treatment, in cases where a decision had been made that withdrawal was in the best interests of the patient. Questions arise about whether a doctor with such an objection has a right to decline to carry out the action to withdraw treatment, and whether he/she would be entitled to decline to participate in other aspects of care for the particular patient. These questions about the responsibilities of doctors with conscientious objections are relevant to other areas of medical practice, and cannot be decided only in relation to withdrawing life-prolonging treatment. It is proposed to raise the issue for substantive discussion in the context of current work to produce a new edition of *Good Medical Practice*. Whatever is decided will be referred to or included in this guidance.

**Concerns about starting then stopping treatment**

15. Paragraph 9 addresses a concern often raised by medical staff. There is a school of thought that sees a distinction between withholding and withdrawing a life-prolonging treatment, with a decision to withdraw (an act) being more culpable than withholding treatment (an omission). Those who make this distinction may find it difficult to contemplate withdrawing a treatment once started. They may prefer to err on the side of withholding treatment, unless there is a high degree of certainty that the treatment would benefit the patient. It is important to point out that case law to date does not make this distinction between withholding or withdrawing a treatment. The legal position is consistent with the professional view that the principal consideration, in deciding how to proceed in a particular case, is whether what is proposed is judged to be in the best interests of the patient (see paragraph 5 of the guidance). Paragraph 9 acknowledges concerns in this area, while drawing attention to the legal position, and reminding doctors of their professional obligations towards the patient.
Non-discrimination

16. Paragraph 10 is included to address concerns, raised in the media on many recent occasions, about claims that some doctors have considered a patient’s age (usually the elderly) or disability (such as patients with Down’s Syndrome) as sufficient grounds in itself to withhold treatment or offer a poorer standard of care. The wording is based on our advice in Good Medical Practice.

Legal principles

17. The text in paragraphs 12–16 is intended to make clear that we do not provide a comprehensive statement of the legal position, while steering doctors to the legal issues which they will need to address. Professor Andrew Grubb has provided expert advice on drafting these sections. We are aware of two recent court cases, involving interpretation of the Human Rights Act 1998 in this area, which may require some changes to the current text before public consultation.

Good practice framework

Clinical responsibility for the decision

18. Paragraph 18 addresses concerns, raised by doctors and patients, about inexperienced junior doctors being expected to make the decision whether to withhold or withdraw a treatment, often without proper guidance from the supervising doctor. It makes clear that responsibility for the decision rests with the senior clinician. This would not prevent responsibility for carrying out the decision being delegated to a junior doctor under proper supervision.

Diagnosis and prognosis

19. Paragraph 19 emphasises the importance of seeking a second opinion on the diagnosis and prognosis in most cases. The examples given are those circumstances where the Committee and Working Group consider difficulties are most likely to arise.

Options for treatment

20. Paragraphs 20-22 again emphasise the circumstances in which a second opinion must be sought. It is partly aimed at addressing earlier concerns that some GPs accustomed to working single-handedly may not consider the need to consult colleagues with more extensive, relevant, or up-to-date expertise. The last bullet point in paragraph 20 requires all doctors to seek a second opinion where they are considering an option which would be certain to lead to the patient’s death.

Emergencies

21. Paragraph 23 recognises that situations can arise where the nature of the patient’s condition, and the urgent need to decide on a course of action, does not allow time to seek a second opinion or to consult with the patient or their family. It avoids unnecessary delay, or the inappropriate starting or continuation of possibly
burdensome procedures, in clearly futile cases or where the patient’s wishes are clearly known.

Choosing between options: competent patients

The Patient’s Views

22. Paragraph 24 reflects the advice in *Seeking Patients’ Consent* and makes clear what are the rights of a competent patient. Paragraph 25 is a reminder to give early consideration to the general care needs of patients, and their wish to be able to plan ahead as much as possible. Paragraph 26 is aimed at ensuring that enough time is allowed for patients to reach well informed decisions and make the necessary plans.

When treatment is not clinically indicated

23. Paragraphs 27-28 address questions which have arisen in relation to decisions about cardio-pulmonary resuscitation as highlighted by recent cases in the media. The Committee decided that, in view of the pressure for a statement on this issue from the GMC, it would be helpful to add an appendix to the guidance to give specific advice on cardio-pulmonary resuscitation. The appendix is discussed at paragraph 32 below.

Choosing between options: patients who are not competent

24. Paragraph 29 on assessing capacity reflects the advice in *Seeking Patients’ Consent*. Paragraph 30 is intended to clarify the different roles and responsibilities of the doctor and those of other people who might reasonably be involved in making decisions on behalf of an incapacitated patient. This is an area where conflict often arises because, for example, medical staff and family members have different views about who in the family has a right to participate in the decision making, or there is uncertainty about how much weight to attach to individual views or about who can make the final decision. Paragraph 31 is an important reminder about respecting confidentiality.

Deciding on best interests

25. The advice in paragraph 32 reflects the guidance in *Seeking Patients Consent*. It also draws attention to changes in the legal position in Scotland under the Adults with Incapacity (Scotland) Act 2000. (The relevant sections come into force in 2001.) Readers are also alerted to similar changes proposed by the Lord Chancellor’s Department for England and Wales, though no legislation has yet been presented.

Disagreements about best interests

26. Paragraph 33 sets out stages for attempting to resolve disagreements. It may mean some hospitals or GP practices having to set up new arrangements for
accessing independent clinical or ethical review. The consultation exercise should provide feedback on any practical difficulties that might arise.

**Communicating decisions**

27. Paragraph 34 aims to ensure that there is no confusion amongst the health care team or other carers about what has been decided. It also deals with concerns that family members may not be given a proper explanation of what was being done for a patient and why, or that their role in providing support towards the end of a patient’s life may not be properly recognised.

**Recording decisions**

28. Paragraph 35 aims to ensure that doctors make adequate records that can serve the needs of all those involved in the patient’s care, and can also provide a good basis for audit - see the advice at paragraph 37 where audit is made compulsory, to ensure the spread of best practice.

**Reviewing decisions**

29. Paragraph 36 should be self explanatory. It would help to avoid situations where unexpected changes in a patient’s condition are slow to be detected, or do not immediately alert carers to the need for a review, for example a patient in a nursing home where the GP usually would visit only infrequently.

**Children**

30. Paragraph 38 is intended to make clear that, whilst the principles in the good practice framework also apply to children, the complexity of the legal position means that doctors should get up to date legal advice before proceeding. The advice on children and consent in our booklet *Seeking Patients’ Consent* is appended as a useful starting point.

**Accountability**

31. The wording of paragraph 39 is in keeping with the approach we are taking in recent GMC guidance documents.

**Appendix B: Good Practice in Decisions about Cardiopulmonary Resuscitation**

32. This applies the guidance in the good practice framework. It takes account of joint guidance published in June 1999 by the BMA, RCN and the Resuscitation Council (UK) and guidance issued more recently by the Department of Health. Together with those documents, it should help to meet the public demand for some form of national guidance against which doctors can be held formally accountable.

**Glossary**

33. The meaning of many key phrases within the guidance which are familiar to a professional audience will not be clear to other readers. In some cases there is a
significant degree of disagreement about interpretation of a phrase, for example what procedures are included in 'basic care'. The glossary explains the meaning being attached to these phrases only for the purposes of the guidance.

Scottish legal position

34. To ensure that the Scottish legal position is properly reflected in the guidance, Lynda Towers (Scottish Executive, Solicitors Department) has agreed to consider what support can be provided during further development of the text.

35. The Committee and Working Group were content that the current draft would provide a sound basis for guidance, subject to any views received from the proposed public consultation exercise.

Recommendation: To consider the text of the draft guidance at Annex D.

Public consultation

36. All recent GMC guidance on substantial issues has been the subject of public consultations. A consultation exercise is unlikely to identify entirely new issues, but would be particularly useful in providing feedback on the practicalities of implementing the guidance. Allowing interested parties the opportunity to comment and contribute might provide a wider base of public support for the guidance in what is a particularly contentious area.

Recommendation: To agree that the draft text should be issued for public consultation.

Resource implications

37. The cost of a consultation exercise based on promotional information in GMC News and on the website, distributing copies to target organisations and anyone else who requests a copy is estimated at £800.
Annex C

Working Group on Withholding and Withdrawing Life-Prolonging Treatment

Membership

Committee members
Professor David Hatch (Chair) - anaesthesia; paediatrics
Dr Pearl Hettiaratchy - psychiatry, elderly
Bob Nicholls - Chair of PPC; lay member
Revd Graham Forbes - lay member

Committee observer
Dr Michael Wilks - BMA Ethics Committee

External members
Professor Andrew Grubb - medical law
Professor Irene Higginson - palliative care
Dr Bill Holmes - general practice
Diana Kingston - clinical nurse specialist, critical care
Stephanie Ellis - Camden CHC
Dr Elaine Gadd - Department of Health, medical ethics policy
Withholding and Withdrawing Life-Prolonging Treatments: Good Practice in Decision-making

This guidance develops the advice in *Good Medical Practice and Seeking Patients’ Consent: the ethical considerations*. It sets out the standards of practice expected when doctors are considering whether to withhold or withdraw life-prolonging treatments.

**Draft 5**
October 2000
Introduction

38. Doctors have a responsibility to make the care of their patients their first concern. This is essential when considering any of the growing range of life-saving or life-prolonging treatments which make it possible to extend the life of patients who, through organ or system failure, might otherwise die. The benefits of modern techniques such as cardiopulmonary resuscitation, renal dialysis, artificial ventilation, artificial nutrition and hydration, are considerable. However they also present doctors, patients and their families, with dilemmas. For example, advanced techniques of life support may be able, in some cases, to sustain life artificially for many years for patients for whom there is little hope of recovery. The quality of life which may follow some treatments might raise questions whether it is in the best interests of the patient to start or continue the treatment.

39. The difficult ethical and legal issues raised by decisions to withhold or withdraw treatments, where this may lead or contribute to the death of a patient, have caused considerable debate amongst the profession, public and in the courts. This has highlighted concerns that some doctors may make these decisions without access to up to date clinical advice; or make judgements about the effect of treatment (or non-treatment) on the quality of life of very young or very old patients which society as a whole may not support. It is clear that patients, their families, and the wider community, want
greater involvement in making these decisions\(^1\), and more guidance on what is considered ethically and legally permissible.

40. The guidance which follows is intended to provide an ethically based framework of good practice for doctors faced with making decisions whether to withhold or withdraw life-prolonging treatment, based on those areas of broad consensus so far established. It takes account of current law in this area, especially that prohibiting killing, euthanasia and assisted suicide. It is therefore based on the premise that, any medical intervention where the doctor’s primary intention\(^2\) is to end the patient’s life is both unlawful and contrary to the ethics of medicine.

**Ethical and legal context**

41. There are a number of ethical and legal issues which must be taken into account in any framework for good practice in this area of decision making. The issues which this document addresses can be summarised as follows:

\(^1\) The House Of Lords (1994) Report of the Select Committee on Medical Ethics recommended that additional safeguards are needed to protect the interests of the
Ethical

- Does the ethical principle requiring doctors to show respect for human life mean that doctors should offer all means at their disposal to prolong a patient's life?

- What are the responsibilities in the decision making process of the patient, doctor, healthcare team, patient's partner, parent, family or other representative? And what weight should be given to the views of each participant?

Legal and practical

- Who is legally accountable for such decisions?

- Given the legal prohibitions against killing, euthanasia and assisted suicide, how does the law view decisions to withhold or withdraw treatment?

- If treatment can lawfully be withheld or withdrawn, is there guidance on when a particular intervention would be regarded as ‘treatment’?

- When should the views of the courts be sought?

**Ethical Principles**

vulnerable, and to ensure that doctors only take these decisions after appropriate
Respect for human life and best interests

42. Doctors have an ethical obligation to show respect for human life and protect the health of their patients. They also have a duty to act always in the best interests of a patient. This means offering those treatments where the possible benefits outweigh any burdens or risks associated with the treatment, and avoiding those treatments where there is no net benefit to the patient. Benefits and burdens are not limited to purely medical considerations, but may include other factors relevant to the circumstances of the particular patient. Prolonging life will usually be in the best interests of a patient, provided that the treatment is not considered to be excessively burdensome or disproportionate in relation to the expected benefits. Withholding or withdrawing treatment may be in the best interests of a patient when the treatment provides no benefit or where the benefits are outweighed by the burdens or risks.

Decisions by competent patients

43. Adult competent patients have the right to decide how much weight to attach to the benefits, burdens or risks, the overall acceptability of any treatment, and the right to refuse treatment even where refusal may result in harm to themselves or in their own death. They can express their wishes about future treatment in an advance statement and, where it is valid and consultation.
clearly applicable, any refusal of treatment given when they were competent must be respected. The wishes of a child who has the capacity to decide whether to consent to or refuse a proposed treatment should normally be respected. A person with parental responsibility, or the courts, may nevertheless authorise treatment which is in the child’s best interests – see Appendix A which gives a fuller statement of the position in relation to children.

**Decisions for patients who lack competence to decide**

44. Where adult patients lack capacity to decide themselves, and have not expressed their wishes in an advance statement, an assessment of the benefits, burdens and risks, and the acceptability of the treatment must be made on their behalf by the doctor, with the patient’s authorised representative where appointed. The healthcare team should be consulted. In addition, wherever possible, so should be the patient’s partner, family members, or other carer, who may be able to offer an insight into the patient’s preferences or an opinion on what would be in the patient’s best interests, based on their knowledge of the patient. In the case of children who lack capacity to decide, a person with parental responsibility may authorise or refuse a treatment where they consider that to be in the child’s best interests. However, the doctor is not bound by such a refusal and may seek a ruling from the court - see Appendix A which also gives advice about proceeding in an emergency.

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2 R v Cox (1992) 12 BMLR 38
Difference of view about best interests

45. Applying these principles may result in different decisions in each case, since patients’ assessments of the likely benefits and burdens or risks, and what weight or priority to give to these, will differ according to their different values, beliefs and priorities. Where patients lack capacity to decide, the doctor, health care team, patient representative, or others involved in making the decision, may reach different conclusions about patients’ values, beliefs and priorities. In these cases, where any significant disagreement about best interests cannot be resolved after ethical or clinical review, legal advice should be sought.

Concerns about starting then stopping treatment

46. Although it is emotionally more difficult for the health care team, carers and family members to withdraw a treatment from a patient rather than decide not to provide a treatment in the first place, this should not be used as a reason for failing to initiate a treatment which may be of some benefit to the patient. Where it has been decided that a treatment is not in the best interests of the patient, relevant case law to date makes no distinction between omitting to start a treatment and acting to withdraw a treatment, and nor does this guidance. There is always a presumption in favour of starting treatment. This is particularly important where time is needed for a proper assessment, in

3 See also glossary definition of ‘best interests’.
emergencies and also where there is doubt about the appropriateness of treatment, the severity of a condition, the likelihood of recovery, or the ability of a particular treatment to benefit the patient. Patients and their families should be reassured that basic care will always be provided.

Non-discrimination

47. Doctors have a duty to give priority to patients on the basis of clinical need, while seeking to make the best use of resources using up to date evidence about the clinical efficacy of treatments. Doctors must not allow their views about, for example, a patient’s age, disability, race, colour, culture, beliefs, sexuality, gender, lifestyle, social or economic status, to prejudice the choices of treatment offered or the general standard of care provided.

Accountability

48. Finally, doctors are ethically responsible to their patients and society at large, while being individually accountable to the GMC for their decisions about care and treatment of patients in this as in other areas of practice.

Legal Principles

4 ‘Authorised representative’ is defined in the glossary.
Case law

49. Doctors have a duty to protect the life and further the health of patients. While current law is not comprehensive in this area, a number of legal judgements on withholding and withdrawing treatment have shown that the courts do not consider that protecting life (the ‘sanctity of life’ principle) always takes precedence over other considerations. The following principles have been established in case law:

- A competent adult patient may decide to refuse treatment even where refusal may result in harm to themselves or in their own death. This right applies equally to pregnant women as to other patients, and includes the right to refuse treatment where the treatment is intended to benefit the unborn child.
- Life prolonging treatment may be lawfully withdrawn from incompetent patients only when commencing or continuing treatment is not in their best interests.
- There is no obligation to give treatment which is futile and burdensome.
- Where a patient has become incompetent, a refusal of treatment made when a patient was competent must be respected, provided it is clearly

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5. ‘Basic care’ is defined in the glossary.
applicable to the present circumstances and there is no reason to believe that the patient has changed his/her mind.10

- For children or adults who lack capacity to decide, assessments of the likely quality of life for the patient with or without a particular treatment may be an appropriate consideration in reaching a view on whether a particular treatment would be more burdensome than beneficial.11

- Artificial nutrition and hydration constitute medical treatment and may be lawfully withdrawn from patients in a permanent vegetative state in certain circumstances.12,13 However, in practice, a court declaration should be obtained.14

- Final responsibility rests with the doctor to decide what treatments are clinically indicated and should be provided to the patient after taking account of the patient's preferences or, in the case of incompetent patients, the views offered by those close to the patient.15

Courts' approach to decision making

50. Case law also suggests that:

10 Re C (Adult: Refusal of Treatment) [1994] 1 WLR 290; Airedale NHS Trust v Bland [1993] 1 All ER 821; Re T (Adult: Refusal of Treatment) [1992] 4 All ER 349.
12 Airedale NHS Trust v Bland [1993] 1 All ER 821; Law Hospital NHS Trust v Lord Advocate 1996 SLT 848.
13 Criteria for determining permanent vegetative state, and when it is appropriate to consider withdrawing artificial nutrition and hydration are given in The Permanent Vegetative State Royal College of Physicians of London. 1996.
14 Airedale NHS Trust v Bland [1993] 1 All ER 821; Law Hospital NHS Trust v Lord Advocate 1996 SLT 848.
• Where a patient’s capacity to consent is in doubt, or where differences of opinion about his or her best interests cannot be resolved satisfactorily, legal advice should be sought.

• When the Court is asked to reach a view on whether it is proper to withhold or withdraw a treatment, the starting point in reaching a decision will be whether the proposed management of the patient satisfies the ‘Bolam test’\(^{16}\), that is whether in the particular circumstances a responsible body of medical opinion would regard it as good practice to manage the patient’s condition in that same way. Ultimately the Court will determine for itself whether treatment or non-treatment is in the patient’s best interests.\(^{17}\)

51. The courts have not addressed the issue of whether artificial nutrition and hydration can be withdrawn from patients who are not in a persistent vegetative state (PVS), or in states closely resembling PVS.

52. It is also important to note that the Human Rights Act 1998 may have implications for this area of medical decision making. Notably, Article 2 requires that a person’s right to life be protected by law; Article 3 prohibits inhuman and degrading treatment; and Article 8 requires respect for private and family life. As relevant case law emerges, the exact scope of these rights and how they may be balanced against one another will become clear. It is clear that doctors’ decisions are likely to be subject to greater scrutiny and the

\(^{16}\) Bolam v Friern Hospital Management Committee [1957] 1 WLR 582.
decision making process will need to be open, transparent and demonstrably rational.

53. Other legislative changes affecting patients’ rights, such as provisions in the Adults with Incapacity (Scotland) Act 2000, mean that the legal position in Scotland, Northern Ireland, England and Wales could diverge significantly in future years. Such changes reinforce the importance of doctors obtaining up to date advice and guidance on the legal as well as clinical issues affecting their practice in this area.

54. Based on the ethical and legal principles above, the guidance below sets out a framework of good practice for reaching, implementing and reviewing decisions on withholding or withdrawing life-prolonging treatments. It identifies other sources of advice where these are known.  

**Good Practice Framework**

*Clinical responsibility for decisions*

55. A decision to withhold or withdraw life-prolonging treatment should be made only by the senior clinician (consultant or general practitioner) in charge of a patient's care, taking account of the views of the patient or those close to the patient as set out in paragraphs 24-38.

*Diagnosis and prognosis*

56. Before a decision is made to withhold or withdraw treatment, as the treating doctor you must carry out a thorough assessment of the patient's condition and the likely prognosis, taking account of current guidance on good clinical practice. You must seek a second opinion for difficult diagnostic assessments such as determining persistent vegetative state and the related prognosis, recognising symptoms associated with treatable psychiatric problems in elderly patients, agreeing a prognosis for patients with multiple underlying conditions. In exceptional circumstances, such as acute life threatening emergencies, where seeking a second opinion is not possible, follow the guidance at paragraph 23.
Options for treatment

57. You must identify appropriate treatment options based on up-to-date clinical evidence about efficacy, side effects and other risks, and referring to any relevant clinical guidelines on the treatment and management of the patient’s condition, or patients with similar underlying risk factors.

58. You must reach a considered judgement on the likely benefits, burdens and risks (including non-clinical), for the particular patient, of each of the treatment (or non-treatment) options identified.

59. Always seek a second opinion from an experienced colleague in cases where:

   • You are uncertain about the range of options.
   • You have difficulty making an assessment of the benefits, burdens and risks of a particular option for the individual patient.
   • Withholding or withdrawing a treatment would be certain to lead to the patient’s death. This would include, for example, artificial nutrition and hydration.

Emergencies
60. In an acute life threatening emergency, where any delay might prejudice the outcome, you may consider that it is not possible to hold consultations - as outlined above and in the rest of this guidance - before making a decision. There should be a presumption in favour of starting treatment (see paragraph 9 above). You should respect the terms of any valid advance refusal which you know about or is drawn to your attention. You should give a clear explanation of the reasons for your decisions about treatment or non-treatment to the patient where they recover sufficiently to understand or – if the patient does not recover - to the patient's partner, family or other carers, except where you know that the patient would have objected to the information being disclosed.

Choosing between options: competent patients

The patient's views

61. Where a patient is competent to participate in decision making, you must discuss with the patient your conclusions about diagnosis, prognosis and which options you consider may be in the patient's best interests. It is for the patient to judge what might be acceptable; and what weight or priority to give to any burdens or risks; and to decide which of the options would be in his/her best interests. You should bear in mind that a competent adult patient's decision to refuse a particular medical intervention must be respected, even where this would result in some harm to themselves or in their own death.
62. Where the possibility of withholding or withdrawing a treatment is being considered as an option, you should discuss with the patient how their care would be managed if such a decision were made. This should include arrangements for providing basic care and other appropriate treatments; what might be their palliative or terminal care needs and how these would be met; the patient's preferences about who should be involved in decision making or in providing additional support if they become incapacitated\(^1\).

*Timing of discussion with patients*

63. You should hold discussions at a time when the patient is best able to understand and retain information. You should allow the patient sufficient time to reflect and ask questions before deciding, and discuss the patient's right to change their mind about the decision.

*When treatment is not clinically indicated*

64. Where there is no clinical indication for a treatment, but not providing it may contribute to, or be seen as contributing to, the patient's death, you must still offer a clear explanation of the implications and discuss the consequences with the patient. This will allow patients the opportunity they need to decide what arrangements should be made to manage the final

\(^1\) For further advice on management and aftercare issues consult publications like: 'Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for decision making', BMA London. 1999. 'Withholding or Withdrawing Life Saving Treatment in Children: A
stages of their illness; and to attend to personal and other concerns which are important in ensuring that the patient can die with dignity\textsuperscript{19}. This applies particularly to decisions about cardiopulmonary resuscitation and artificial nutrition and hydration. (Fuller guidance on resuscitation is given in Appendix B.)

65. Clearly discussions about the possibility of withholding or withdrawing a potentially life prolonging treatment may be difficult and distressing. But this does not mean that discussion should be avoided, rather that it should be handled sensitively and with appropriate support being provided to the patient\textsuperscript{20}. Where appropriate you should consult with those close to the patient about the best means of achieving this. Where patients clearly indicate that they do not wish to know or discuss the details, you should not force this information on them. However you should still provide the other information about their condition and its treatment which they need for decision making.

**Choosing between options: patients who are not competent**

*Assessing capacity to decide*

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\textsuperscript{19} For advice on aftercare issues which patients may want to explore consult publications like 'Clinical Guidelines in Palliative Care', National Council for Hospice and Specialist Palliative Care. 'The Future of Health and Care of Older People', Age Concern. 2000.

\textsuperscript{20} Advice on effective communication with patients can be found in publications such as ‘Seeking Patients’ Consent: the ethical considerations’ GMC. 1999. ‘Breaking Bad News’ Royal College of Physicians. 1998.
66. Where there are doubts about a patient’s capacity to make a decision, you should carry out a thorough assessment, taking into account any legal tests of capacity21 and consulting relevant professional guidelines22. You should provide any assistance a patient might need to enable them to reach and/or communicate a decision. You should seek a second opinion where appropriate, for example in assessing whether an elderly patient’s behaviour is symptomatic of their condition or indicates a depressive illness. Where a patient’s capacity to decide remains in doubt, you must seek legal advice, which may include asking a court to determine capacity.

Who decides for the patient

67. Where a patient lacks capacity to decide, you must check whether they have made an advance statement of their wishes. If they have and it is valid and clearly applicable, any refusal of treatment given when they were competent must be respected. Otherwise you – as the senior clinician responsible for the patient’s care – must make a decision about what course of action would be in the patient’s best interests, consulting the patient’s authorised representative where appointed. You should also consult the healthcare team and, wherever possible, the patient’s partner, family members, or other carer, as they may be able to provide insight into the
patient's preferences or have greater knowledge of the patient's life to offer an opinion on what would be in the patient's best interests.

68. You should pay due regard to any previous wishes of the patient about not disclosing information to particular individuals. Otherwise, your discussions about which option is in the patient's best interests should follow the principles in paragraphs 24-28. You should consider what support could be provided to those caring for the patient, including family members.

Deciding on best interests

69. Your consultation with the healthcare team and patients' representatives should aim to achieve consensus on what course of action would be in the best interests of incapacitated patients. The factors considered in assessing best interests should take into account relevant statutory requirements23, and guidance from the GMC24, supplemented by more detailed professional guidance where available.

Disagreements about best interests

70. Where significant disagreement arises about a patient's best interests, you should seek a clinical or ethical review independent of the health care team. If this fails to resolve disagreement, you must seek legal advice on


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whether it is necessary to apply to the court for a ruling. (See the legal references in paragraphs 12 - 16.)

**Communicating decisions**

71. Whatever decision is made, you must ensure that all those consulted, and especially those responsible for delivering care, are informed of the decision and are clear about the goals and the agreed management plan. It is particularly important where treatment is to be withheld or withdrawn, that everyone involved is clear about the arrangements for providing appropriate palliative or terminal care, and their roles. You should discuss what the role of the family or other carers will be, and what support they will receive from yourself or the healthcare team.

**Recording decisions**

72. You must ensure that decisions are properly documented, including the relevant clinical findings; details of discussions with the patient, health care team, or others involved in decision making; details of treatment given with any agreed review dates; outcomes of treatment or other significant factors which may affect future care. You should record the information at the time of, or soon after, the events described. The record should be legible, clear, accurate and unambiguous, for example avoiding abbreviations or other terminology that may cause confusion to those providing care. You should
ensure that the records are appropriately accessible to team members and others involved in providing care to the patient.

**Reviewing decisions**

73. You must review your decisions, at appropriate intervals during the agreed treatment or the period of palliative or terminal care, to determine whether the goals of treatment or the management plan remain appropriate. You should seek a second opinion where, for example, the patient’s condition is not progressing as expected.

**Audit**

74. In this area of decision making, you must carry out clinical and medical audit of the process, which can improve your own and others’ knowledge about the outcomes of different treatment and non-treatment decisions and ensure the spread of best practice.

**Children**

75. The general principles of good practice set out above also apply to decision making in cases involving children, including premature babies where the decisions may be particularly difficult for everyone involved. However, you should note that assessments of a child’s capacity to make
their own decision, and the extent of the authority which can be exercised by those with parental responsibility, are issues governed by statute and case law which vary significantly between Scotland, England and Wales, and Northern Ireland. You should consult Appendix A for the GMC’s current guidance on children and consent, and seek further legal and professional advice where necessary. In all cases you, and others making decisions on behalf of a child, have a duty to consider only those options which are in the best interests of the child.

Accountability

76. If you decide not to follow the guidance in this document, you must be prepared to explain and justify your actions and decisions, to patients and their families, your colleagues and, where necessary, the courts and the GMC.
Children: Consent for treatment


**Children**

You must assess a child’s capacity to decide whether to consent to or refuse a proposed investigation or treatment before you provide it. In general, a competent child will be able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment. Your assessment must take account of the relevant laws or legal precedents in this area\(^\text{25}\). You should bear in mind that:

- at age 16 a young person can be treated as an adult and can be presumed to have capacity to decide.
- under age 16 children may have capacity to decide, depending on their ability to understand what is involved\(^\text{26}\).

\(^{25}\) You should consult your medical defence body or professional association for up to date advice.
\(^{26}\) Age of Legal Capacity (Scotland) Act 1991 (Section 2.4); Gillick v West Norfolk and Wisbech AHA [1985]
• where a competent child refuses treatment, a person with parental responsibility or the court may authorise investigation or treatment which is in the child’s best interests. The position is different in Scotland, where those with parental responsibility cannot authorise procedures a competent child has refused. Legal advice may be helpful on how to deal with such cases.

Where a child under 16 years old is not competent to give or withhold their informed consent, a person with parental responsibility may authorise investigations or treatment which are in the child’s best interests.\(^{27}\) This person may also refuse any intervention, where they consider that refusal to be in the child’s best interests, but you are not bound by such a refusal and may seek a ruling from the court. In an emergency where you consider that it is in the child’s best interest to proceed, you may treat the child, provided it is limited to that treatment which is reasonably required in that emergency.

\(^{27}\) This also applies to young people between 16 and 18 years old, except in Scotland.
Appendix B

Good Practice in Decisions about Cardiopulmonary Resuscitation

1. Doctors have a responsibility to ensure that all patients are treated with consideration and care, and that their right to be fully involved in decisions about their treatment and care is respected. This applies equally to decisions about cardiopulmonary resuscitation (CPR) where a decision not to provide CPR, though justifiable on clinical grounds, will have serious implications for the patient and the patient's family and other carers.

2. Clearly discussions about circumstances in which CPR may be withheld can be difficult and distressing. However failing to involve the patient or, where appropriate, the patient’s family or other carers before reaching a decision often causes more distress than tackling the issue sensitively. Whilst the final decision about the merits of resuscitation rests with the consultant or general practitioner in charge of the patient’s care, good communication between the doctor, patient and carers, is the key to ensuring that the patient's rights are respected, and misunderstanding and dissent can be minimised.

28 See Good Medical Practice (July 1998) and Seeking Patients’ Consent: the ethical considerations (November 1998)
3. Advice on when it is appropriate to consider making a decision not to resuscitate a patient (a DNR order) is available from professional bodies and the Department of Health. It is important to identify patients where DNR orders may be considered, at the earliest opportunity, and to involve them (when competent) and the health care team in making any advance decision about circumstances when CPR would be withheld. Where patients lack capacity to decide, their authorised representative (where appointed), parent, partner, other family or carer, should be consulted, taking account of any request made by the patient when competent not to discuss his/her care with particular individuals.

4. A senior member of the team should record fully any advance decision not to resuscitate a patient, including the basis on which the decision was reached. The decision should be communicated to all those involved in providing care to the patient. It should be made clear to the patient and all concerned that the provision of all other appropriate treatment and care would remain unaffected by a decision to withhold CPR. DNR orders should be subject to regular review, to ensure they remain appropriate.

5. CPR decisions should be subject to audit to improve knowledge about the outcomes of treatment and non-treatment decisions and ensure the spread of good practice.

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**Glossary:** This defines terms used within this document. These definitions have no wider or legal significance

**Advance statements:** Also referred to as ‘advance directives’ or ‘living wills’, these are statements made by a competent person about their preferences for treatment (or non-treatment) in circumstances in the future where they are no longer competent to express their own wishes.

**Artificial nutrition and hydration:** This term is commonly used in medicine to refer to techniques such as the use of nasogastric tubes and gastrostomies to provide a patient with nutrition and hydration where there is a problem in a patient’s swallowing process. A distinction is generally made between such ‘artificial’ means and ‘ordinary’ means, such as a cup or spoon, used to deliver food or drink into a patient’s mouth for swallowing - oral nutrition and hydration.

**Authorised representative:** A patient who has lost capacity to make decisions may have previously indicated whom they wish to represent their views or take decisions on their behalf. In Scotland currently a tutor-dative with appropriate authority can make decisions on behalf of a patient. When relevant provisions in the Adults with Incapacity (Scotland) Act 2000 come into force in 2001, a court appointed guardian or a third party granted continuing powers of attorney may be given authority to make medical decisions on behalf of an incapacitated adult patient. There are similar proposals by the Lord Chancellor’s Department for England, Wales and
Northern Ireland which would make it possible in future for the courts to appoint a manager, or for an individual to grant continuing powers of attorney allowing a third party to make health care decisions on their behalf when incapacitated. However, legislation has not yet been presented to put this into effect.

**Basic care:** Sometimes also referred to as ‘personal care’ or ‘nursing care’, there is no legal or commonly accepted definition of ‘basic care’. The British Medical Association have offered a useful definition of basic care as covering procedures or medications which are solely or primarily aimed at providing comfort to the patient or alleviating that person’s pain, symptoms or distress. These would include the offer of oral nutrition and hydration.

**Best interests:** There is a general duty on doctors to provide only those treatments which serve patients’ best interests. A treatment will be in the best interests of a patient where it may benefit the person, and where the benefit(s) outweigh(s) any burdens or risks associated with the treatment. Benefits and burdens are not limited to purely medical considerations, but may include other factors relevant to the circumstances of the particular patient, for example the patient’s assessment of their quality of life if they accept or refuse a particular treatment.

**Life-prolonging treatment:** These are treatments which have the potential to save or extend the life of a patient who might otherwise die through organ or system failure. These include for example cardiopulmonary resuscitation,
artificial ventilation, renal dialysis, chemotherapy, artificial nutrition and hydration, antibiotics for life threatening infections.

**Withholding or withdrawing treatment:** Withholding (not starting) is sometimes differentiated from withdrawing (not continuing) a particular treatment. Relevant case law to date does not make this distinction between withholding or withdrawing treatment and nor does this guidance.