

Withholding and withdrawing - guidance for doctors

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This guidance develops the advice in [Good Medical Practice \(2006\)](#). It sets out the standards of practice expected of doctors when they consider whether to withhold or withdraw life-prolonging treatments.

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Introduction

1. 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-prolonging treatments which make it possible to extend the lives of patients who, through organ failure or other life-threatening conditions, might otherwise die.

2. The benefits of modern techniques such as cardiopulmonary resuscitation, renal dialysis, artificial ventilation, and [artificial nutrition and hydration](#), are considerable. However, life has a natural end and the existence of such techniques presents doctors, patients and their families with dilemmas.

3. Dilemmas arise where, for example, advanced techniques of life support may be able, in some cases where patients are in a permanent vegetative state or similar condition, to sustain life artificially for many years with little or no hope of recovery. In other cases, they may simply prolong the dying process and cause unnecessary distress to the patient. In these instances the question arises as to whether it is in the best interests of the patient to start or continue the treatment. Reaching a satisfactory answer may mean addressing a number of difficult ethical and legal issues.

4. The main questions that arise are:

- Whether the ethical principle requiring doctors to show respect for human life would mean that doctors should offer all means at their disposal to prolong a patient's life? Or would it allow for the possibility of withholding or withdrawing a life-prolonging treatment?
- Are there circumstances in which withholding or withdrawing life-prolonging treatment would be unlawful?
- What are the responsibilities in the decision-making process of the patient, doctor, healthcare team, family members and other people who are close to the patient? And what weight should be given to their views?

5. These issues have caused considerable debate amongst the profession, public and in the courts, highlighting a number of concerns within the wider community. These include concerns about:

- the possibility of over- or under-treatment towards the end of life;
- concerns that some doctors may make decisions about life-prolonging treatments without access to up to date clinical advice; and
- concerns that doctors may make judgements about the appropriateness of treatment (or non-treatment) on a quality of life basis regarding patients, particularly the very young or very old, which patients or society as a whole may not support.

It is also clear that the profession and patients want more guidance on what is considered ethically and legally permissible in this area; and that patients and their families want greater involvement in making these decisions², with better arrangements to support them when facing these distressing situations.

6. The guidance which follows first sets out a number of guiding principles (Part 1: paragraphs 9-30), and then provides a framework for putting the principles into practice (Part 2: paragraphs 32-95) when doctors are faced with making a decision whether to withhold or withdraw a life-prolonging treatment. It includes advice about the need to ensure that there is proper care for dying patients, and that their families and others close to them are involved in that care where appropriate.

7. The guidance is based on long established ethical principles which include doctors' obligations to show respect for human life; protect the health of their patients; and to make their patients' best interests their first concern (as outlined in paragraph 9). It takes account of those areas of broad consensus so far established within the Council, the medical profession and the public about what can be regarded as good practice in applying the principles to decisions about life-prolonging treatment.

8. Good practice also encompasses doctors' obligation to work within the law. The guidance takes account of law affecting practice in this area, in particular the law prohibiting killing (including euthanasia) and assisted suicide. A brief summary of the current legal background against which decisions should be made about withholding or

withdrawing treatment is provided at Appendix A. However, it is not intended as a substitute for up to date legal advice in individual cases. So wherever there is uncertainty about how a particular decision might be viewed in law, legal advice must be sought, for example from a medical defence body or employer's solicitor.

Part 1: Guiding principles

Respect for human life and best interests

9. Doctors have an ethical obligation to show respect for human life; protect the health of their patients; and to make their patients' best interests their first concern. 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.

10. Benefits and burdens for the patient are not always limited to purely medical considerations, and doctors should be careful, particularly when dealing with patients who cannot make decisions for themselves, to take account of all the other factors relevant to the circumstances of the particular patient. It may be very difficult to arrive at a view about the preferences of patients who cannot decide for themselves, and doctors must not simply substitute their own values or those of the people consulted.

11. 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. Not continuing or not starting a potentially life-prolonging treatment is in the best interests of a patient when it would provide no net benefit to the patient. In cases of acute critical illness where the outcome of treatment is unclear, as for some patients who require intensive care, survival from the acute crisis would be regarded as being in the patient's best interests.

End of natural life

12. Life has a natural end, and doctors and others caring for a patient need to recognise that the point may come in the progression of a patient's condition where death is drawing near. In these circumstances doctors should not strive to prolong the dying process with no regard to the patient's wishes, where known, or an up to date assessment of the benefits and burdens of treatment or non-treatment.

Adult patients who can decide for themselves

13. Adult competent³ patients have the right to decide how much weight to attach to the benefits, burdens, risks, and the overall acceptability of any treatment. They have the right to refuse⁴ treatment even where refusal may result in harm to themselves or in their own death, and doctors are legally bound to respect their decision⁵. Adult patients who have the capacity to make their own decision can express their wishes about future treatment in an advance statement.

Adult patients who cannot decide for themselves

14. Any valid advance refusal of treatment - one made when the patient was competent and on the basis of adequate information about the implications of his/her choice - is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind.

15. Where adult patients lack capacity to decide for themselves, an assessment of the benefits, burdens and risks, and the acceptability of proposed treatment must be made on their behalf by the doctor, taking account of their wishes, where they are known. Where a patient's wishes are not known it is the doctor's responsibility to decide what is in the patient's best interests. However, this cannot be done effectively without information about the patient which those close to the patient⁶ will be best placed to know. Doctors practising in Scotland need additionally to take account of the Scottish legal framework for making decisions on behalf of adults with incapacity⁷.

Choosing between options: difference of view about best interests

16. 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 patients' different values, beliefs and priorities. Doctors must take account of patients' preferences when providing treatment. However, where a patient wishes to have a treatment that - in the doctor's considered view - is not clinically indicated, there is no ethical or legal obligation on the doctor to provide it. Where requested, patients' right to a second opinion should be respected.

17. Where a patient lacks capacity to decide, the doctor, health care team or those close to the patient involved in making the decision, may reach different conclusions about the patient's preferences and what course of action might be in the patient's best interests. In these cases it is important to take time to try to reach a consensus about treatment and it may be appropriate to seek a second opinion, or other independent or informal review.

18. In the rare circumstances where any significant disagreement about best interests cannot be resolved, legal advice should be sought on whether it is necessary to apply to the court for a ruling. Doctors practising in Scotland would need to take account of the statutory procedures for resolving disagreements.

Concerns about starting then stopping treatment

19. Although it may be emotionally⁸ more difficult for the health care team, and those close to the patient, to withdraw a treatment from a patient rather than to 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, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it.

20. Where patients lack capacity to make decisions about treatment, and there is a reasonable degree of uncertainty about the appropriateness of providing a particular treatment, treatment which may be of some benefit to the patient should be started until a clearer assessment can be made. It must be explained clearly to all those involved in caring for the patient that the treatment will be reviewed, and may be withdrawn at a later stage, if it is proving to be ineffective or too burdensome for the patient.

21. This is particularly important where time is needed for consultation and a more detailed assessment, in emergencies, and also where there is doubt about the severity of a condition, the likelihood of recovery, or the ability of a particular treatment to benefit the patient. In these cases patients, their families and carers should be reassured that symptom assessment and relief and nursing care⁹ would always be provided, whatever decision is made about particular treatments.

Artificial nutrition and hydration

22. Decisions involving artificial nutrition or hydration¹⁰ may be particularly difficult and/or contentious. In part this is because the benefits and burdens of either nutrition or

hydration may not be well known and involve difficult assessments of the patient. For example, patients in the later stages of a progressive or severely disabling condition, where their body systems begin to shut down, may increasingly lose interest in food or drink. For some patients not taking nutrition or hydration may be part of the natural dying process. Problems in making assessments can arise because some patients may under-report their symptoms, while perceptions may differ between doctors, members of the health care team and those close to a patient, about the presence or severity of symptoms such as pain.

23. In the face of such uncertainties, there may be concern about the possibility that a patient who is unconscious or semi-conscious, and whose wishes cannot be determined, might experience distressing symptoms and complications or otherwise be suffering, because their needs for nutrition or hydration are not being met. Alternatively there may be concern that attempts to meet the patient's needs may cause avoidable suffering. For some people there may be emotional difficulties in deciding not to provide what they see as basic nurture for the patient.

24. In view of these considerations, it is essential that doctors ensure that those involved in making the decision are provided with clear and up to date information about what is known of the benefits, burdens and risks of providing nutrition and hydration through artificial means, and information about the basis on which the particular patient's needs have been assessed. It is also essential that doctors making decisions about artificial nutrition and hydration take careful account of the principles of good practice set out in this guidance (see also advice at paragraphs 78-83).

Non-discrimination

25. 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.

Care for the dying

26. Patients who are dying should be afforded the same respect and standard of care as all other patients. Patients and their families and others close to them should be treated with understanding and compassion. Where the likely progression of a patient's condition is known, and their death is seen as an inevitable outcome, it is important to ensure that the patient's palliative care or terminal care needs are identified and met appropriately. This should include consideration of their wishes regarding such matters as the appropriate place for receiving care (which may affect the treatment options available), and their needs for religious, spiritual or other personal support. Every attempt should be made to ensure that they are afforded privacy, dignity, and good quality care in comfortable surroundings. This includes assessment of, and adequate relief from, pain and other distressing symptoms, and appropriate support and nursing care.

27. Discussion about the dying process allows patients the opportunity they may want to decide what arrangements should be made to manage the final stages of their illness, and to attend to personal and other concerns that they consider important towards the end of their life¹¹.

Conscientious objections

28. Where a decision to withhold or withdraw life-prolonging treatment has been made by a competent adult patient, or made by the senior clinician responsible for the care of a patient who lacks capacity to decide (following discussions with those close to the patient

and the health care team) doctors who have a conscientious objection to the decision may withdraw from the care of that patient. In doing so they must ensure, without delay, that arrangements have been made for another suitably qualified colleague to take over their role, so that the patient's care does not suffer.

29. Junior doctors in this position must make their conscientious objection known to the doctor responsible for the patient's care who should then ensure that arrangements are made for another colleague to take over from the junior doctor.

Accountability

30. Doctors are responsible to their patients and society at large, while being individually accountable to the GMC and in the courts for their decisions about withholding and withdrawing life-prolonging treatments.

Part 2: Good practice framework

31. The guidance which follows provides a framework for putting the principles into practice in reaching, implementing and reviewing decisions on withholding or withdrawing life-prolonging treatments. It identifies other sources of advice where these are known.

Clinical responsibility for decisions

32. If you are the consultant or general practitioner in charge of a patient's care, it is your responsibility to make the decision about whether to withhold or withdraw a life-prolonging treatment, taking account of the views of the patient or those close to the patient as set out in paragraphs 41-48 and 53-57. Exceptionally, in an emergency where the senior clinician cannot be contacted in time, if you are an appropriately experienced junior hospital doctor or deputising general practitioner you may take responsibility for making the decision, but it must be discussed with the senior clinician as soon as possible.

Diagnosis and prognosis

33. 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 and the views and assessments of the clinical team.

34. Where there is significant disagreement within the clinical team, you must do your best to resolve it and to ensure clarity and consistency in the information provided to the patient or those close to the patient.

35. You should always give consideration to seeking a second opinion. You must seek a second opinion in cases where you are not sufficiently experienced or knowledgeable, or where there is significant disagreement within the team about clinical aspects of a patient's care. In life threatening emergencies, where seeking a second opinion is not possible, follow the guidance at paragraphs 39-40.

Options for treatment

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

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

38. Always consult a clinician with relevant experience (who may be from another discipline such as nursing) in cases where:

- You and the health care team have limited experience of a condition.
- You are in doubt about the range of options, or the benefits, burdens and risks of a particular option for the individual patient.
- You are considering withholding or withdrawing artificial nutrition or hydration from a patient who is not imminently dying, although in a very serious condition, and whose views cannot be determined (see paragraph 81 below).
- You and other members of the health care team have a serious difference of opinion about the appropriate options for a patient's care.

Emergencies: with limited information about the patient

39. A life-threatening emergency might arise where you and the healthcare team have no previous knowledge of, or inadequate information about, the patient's medical history or wishes regarding treatment, and where any delay might prejudice the outcome. In these circumstances you may consider that it is not possible to obtain all relevant information or hold any consultations - as outlined in this guidance - before making a decision.

40. In deciding whether to withhold or withdraw a particular treatment you must respect the terms of any valid and applicable advance refusal that is in the patient's notes or is drawn to your attention. Otherwise you must make a considered judgement about the patient's best interests. Where there is a reasonable degree of uncertainty about the appropriateness of any treatment, you should follow the advice at paragraph 20 above. You should give a clear explanation of the reasons for your decisions to the patient where they recover sufficiently to understand or - if the patient does not recover - to those close to the patient.

Choosing between options: patients who can decide for themselves

Seeking the patient's views

41. Where a patient has the capacity to decide, you must raise with the patient the need to discuss 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 weight or priority to give to any benefits, burdens or risks; and to decide whether any of the options would be acceptable.

42. You should bear in mind that you are bound to respect an adult patient's competently made refusal of treatment even where complying with the decision will lead to the patient's death. If a specific treatment is requested which, in your considered view is clinically inappropriate, you are not legally or ethically bound to provide it. However, you should give the patient a clear explanation of the reasons for your view, and respect their request to have a second opinion.

43. Where the possibility of withholding or withdrawing a life-prolonging treatment is an option, you should offer the patient the opportunity to discuss how their care would be managed if such a decision were made. This should include:

- arrangements for providing nursing care and other appropriate treatments;

- the patient's preferences about who should be involved in decision making or in providing additional support if they become incapacitated;
- what might be their palliative or terminal care needs should death become inevitable and how these would be met¹².

Discussions of this sort, handled sensitively, may help to build trust and provide an opportunity for you to get information about the patient's values and priorities that might be helpful in later decision making.

Sensitive handling of discussions

44. 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 patient¹³. You should ensure the patient knows that they can invite a relative or other person they trust, including a religious or spiritual adviser, to be present during the discussion.

45. Discussions of this kind may need to be conducted over several meetings. 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.

46. Where patients clearly indicate that they do not wish to know about or discuss particular aspects of their condition or treatment, you should not force this information on them. However, you should explain the impact this might have on decision making; explore whether they have unmet needs for support; and do your best to clarify their wishes about how treatment decisions should be made in these circumstances.

47. Where a patient has an existing condition and the likely progression of the disorder is known, for example in some forms of cancer or Alzheimer's disease, you should consider formulating an advance care plan with the patient and the health care team, to allow as much time as possible for the issues to be explored sensitively and effectively. A record of the plan should be available to the patient and others involved in their care, so that everyone is clear about what has been agreed.

48. The advice about sensitive handling is particularly important in relation to decisions about cardiopulmonary resuscitation, and may be relevant to some decisions about artificial nutrition and hydration (see also paragraphs 78-94).

Choosing between options: patients who cannot decide for themselves

Assessing capacity to decide

49. In cases where the dying process itself affects capacity, the correct course of action for the patient may have been decided previously, following the guidance above and the principles in Part 1. Where no such advance care plan has been agreed, or the plan has not been reviewed recently or is not relevant to the patient's current condition, you should follow the advice below.

50. Where patients have difficulty retaining information, communicating their views or are only intermittently competent, you should provide any assistance a patient might need to enable them to reach and communicate a decision. Failure to communicate may not be due to incapacity. The fact that the patient's choice appears irrational or does not accord with your own or others' views of what is in the patient's best interests, is not evidence in itself that a patient lacks capacity.

51. Where there are doubts about a patient's capacity to make a decision, you should carry out a thorough assessment consulting relevant professional guidelines¹⁴, and taking into account any legal tests of capacity¹⁵. Where appropriate, you should seek a second opinion - for example, as described in paragraph 38 above. Where these steps have been taken and a patient's capacity to decide remains in doubt, you must seek legal advice, which may include asking a court to determine capacity.

52. Generally you should start any necessary treatment, which is considered to be of some benefit to the patient, whilst the patient's capacity is being determined. This decision must be reviewed in the light of the outcome of the assessment. However, if you are practising in Scotland, only treatment which is necessary for the preservation of the patient's life or to prevent serious deterioration in the patient's health should be started whilst capacity is being determined.

Meeting the responsibility for assessing the patient's best interests

53. Where a patient lacks capacity to decide, you should take reasonable steps to ascertain whether they have previously expressed their wishes in an advance statement, as described at paragraphs 14-15. You must respect any valid and clinically relevant advance refusal of treatment where you have no reason to believe that the patient has changed his/her mind. In making this assessment, it is necessary to consider whether the patient had foreseen the particular circumstances which have subsequently materialised, or would have been aware of and weighed up any advances in treatment options since their decision was made.

54. Where a patient's wishes are not known and you are not aware of an advance refusal, you - as the senior clinician responsible for the patient's care - have responsibility to make a decision about what course of action would be in the patient's best interests. However, you should consult the healthcare team and those close to the patient for any information that may be relevant to the decision, including their views about what the patient's wishes might have been. You should pay due regard to any previous wishes of the patient about not disclosing information to particular individuals.

55. If the patient is new to you at the time decisions are needed, you must satisfy yourself as to whether such consultations have previously been carried out and find out what has been agreed. If you are practising in Scotland you should take steps to find out whether someone has been appointed to make health care decisions on behalf of the patient and seek their views.

Aiming for a consensus

56. Your discussions about treatment and how best to manage the patient's palliative or other care needs should take account of the considerations set out in paragraphs 41-48. You should take time to try to reach a consensus about treatment. In doing so, you should be careful to explain the participants' roles in reaching a decision and where ultimate responsibility for the decision rests. You should give careful consideration to how much weight it would be reasonable to attach to each person's views.

57. You should do your best to ensure that participants in the decision making have access to any additional support that might be needed, and are aware of any local arrangements for independent review should it become necessary. It may be helpful in trying to reach agreement, for those involved to be provided with some information about the ethical and legal considerations which may be relevant to the decision making, including making available copies of this and other relevant guidance.

Resolving disagreements about best interests

58. It is usually possible to reach a consensus about treatment, given adequate time for discussions between the parties. Individuals may be helped by the opportunity to consult others, medical or non-medical, whose views they respect. In complex cases where it is difficult to reach agreement, or cases where particular individuals participating in the decision-making advance strong arguments as to why an option may be considered controversial, you may also find it helpful to seek multi-disciplinary clinical or ethical review¹⁶, independent of the healthcare team.

59. Where informal review fails to resolve any significant disagreement, you must seek legal advice. This may be available from your Trust or other employing organisation, or your defence body. If you are practising in Scotland and a dispute arises which cannot be resolved informally, you should take legal advice on the statutory procedures for dispute resolution. Patients, or those close to the patient where appropriate, should be informed as early as possible of any decision to seek independent review or a legal opinion, so that they have the opportunity to participate or can be represented.

Communicating decisions

60. Whatever decision is made, you must do your best to ensure that all those consulted, and especially those responsible for delivering care, are consistently informed of the decision and are clear about the goals and the agreed care plan. You should check that hand-over arrangements between professional and other carers include suitable arrangements for passing on the information.

61. It is particularly important that where a patient's death is seen as an inevitable outcome of a decision to withhold or withdraw treatment, 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; what religious, spiritual or other personal support the patient might need; and what support the patient and those close to the patient will receive from yourself or the healthcare team.

62. You should bear in mind that, in circumstances where individuals may be under stress, any important information provided verbally might need to be reinforced in writing.

Recording decisions

63. 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; and 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 the patient, team members and others involved in providing care to the patient.

Reviewing decisions

64. 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 care plan remain appropriate in the patient's present condition. In doing so, you should talk to the patient where possible, and consult those involved in the patient's care.

65. You should consider seeking a second opinion where, for example, the patient's condition is not progressing as expected. Clinical scenarios may change rapidly and it may

become necessary to restart treatment that has been withheld, or vice versa. You also should bear in mind that patients might change their minds about decisions.

Audit and education

66. As in other areas of practice, you must participate in clinical audit of your decisions to help improve knowledge of the outcomes of treatment and non-treatment decisions. Where possible you should help to disseminate best practice, for example, by contributing to the education of students and colleagues about good practice in this area.

Areas for special consideration

Children

67. All the advice in this booklet - the guiding principles, the good practice framework, the advice on artificial nutrition and hydration and on cardiopulmonary resuscitation - also applies to decision making in cases involving children. This includes premature babies and children with disabilities where the decisions may be particularly difficult for everyone involved.

68. In all cases you, and others involved in making decisions on behalf of a child, have a duty to consider what is in the child's best interests on the basis of an assessment of the benefits, burdens and risks for the child. Children's roles in determining what their interests are, and their preferences in relation to treatment, increase with maturity and experience. You should always encourage and help them to understand what is proposed and to participate in decision making as much as they are able and willing to do so.

69. You must assess a child's capacity to decide whether to consent to or refuse a proposed investigation or treatment. In general, children can be considered as having capacity to make a particular decision where they are able to understand the nature, purpose and possible consequences of the proposed investigation or treatment, as well as the consequences of non-treatment.

70. You must also take account of the relevant laws or legal precedents in this area¹⁷, which vary significantly between Scotland, England and Wales, and Northern Ireland. In particular 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 involved¹⁸.
- Where a child lacks capacity to decide, a person with parental responsibility for the child may authorise or refuse treatment where they consider that to be in the child's best interests.

71. The wishes of a child who has the capacity to decide whether to consent to or refuse a proposed treatment should normally be respected. However, the legal position in England and Wales means that, in some circumstances where a child has made a competent refusal of a treatment, a person with parental responsibility, or the courts, may nevertheless authorise the treatment where it is in the child's best interests¹⁹. You may need to seek legal advice on how to deal with such cases.

72. Where a child lacks capacity to make his or her own decision, you should note that authorisation given by one person with parental responsibility cannot be vetoed by a refusal from another person who also holds parental responsibility. In such circumstances you should do your best, in the child's interest, to try to achieve a consensus between those with parental responsibility.

73. It is important that you work sensitively, and in partnership with the child (where that is possible), those who have parental responsibility for the child, members of the healthcare team and other carers, and aim to achieve consensus with them about the best course of action. You should take steps to ensure that those who have a share in the responsibility for making decisions are clear about their roles. As the treating clinician you will take the lead in judging the clinical factors, and the parents will lead in judging more generally what might be in the child's best interests.

74. When considering how best to provide the information and support needed by a child's parents or other carers, and in trying to resolve any significant disagreements amongst those involved in the decision making, you should follow the guidance at paragraphs 44-48 and 53-59 above. Remember that effective communication, careful deliberation, compassion and sensitivity are particularly important in cases involving children²⁰.

75. Where there is disagreement between those with parental responsibility and the healthcare team and this cannot be resolved satisfactorily through informal review, you should seek legal advice about obtaining a ruling from the courts.

76. Where none of those holding parental responsibility are willing to authorise treatment, you should consider yourself bound by their refusal unless you obtain a ruling from the court. In an emergency where you consider that it is in the child's best interests to provide treatment, you may treat the child provided it is limited to that treatment which is reasonably required either to save the child's life, or to prevent deterioration in the child's health.

77. This advice takes account of the legal position at the time of writing this guidance, but you should take steps to ensure access to up to date legal advice and seek specific advice in any cases of doubt.

Artificial nutrition and hydration

78. Where a patient has a problem in taking fluids or food orally, you must carry out an appropriate assessment of their condition and their particular requirements for nutrition or hydration. There are a number of means which you should consider for meeting the patient's assessed needs, including nasogastric tube, percutaneous endoscopic gastrostomy (gastric 'PEG'), subcutaneous hydration, or intravenous cannula, all commonly termed 'artificial' nutrition or hydration. However, the benefits and burdens are different for artificial nutrition and artificial hydration and you should assess these separately. In doing so you should take and follow up to date professional advice on the particular clinical considerations affecting respectively artificial nutrition and artificial hydration²¹.

79. In all cases you should assess the patient for the presence of distressing symptoms, for example signs of pain, breathing difficulties, confusion, and dry mouth. Symptoms should be alleviated appropriately following up to date professional guidance²².

80. In deciding which of the options for providing artificial nutrition or hydration are appropriate in meeting a patient's assessed need, you must ensure that the patient (where able to decide), the health care team, and those close to the patient (where the patient's wishes cannot be determined), are fully involved in the decision making. You should take appropriate steps to help those participating in the decision making to understand your assessment of the patient's requirements for nutrition or hydration, and any uncertainties underlying the options you consider appropriate for meeting those needs.

81. Where patients have capacity to decide for themselves, they may consent to, or refuse, any proposed intervention of this kind. In cases where patients lack capacity to decide for themselves and their wishes cannot be determined, you should take account of the following considerations:

Where there is a reasonable degree of uncertainty about the likely benefits or burdens for the patient of providing either artificial nutrition or hydration, it may be appropriate to provide these for a trial period with a pre-arranged review to allow a clearer assessment to be made.

Where death is imminent, in judging the benefits, burdens or risks, it usually would not be appropriate to start either artificial hydration or nutrition, although artificial hydration provided by the less invasive measures may be appropriate where it is considered that this would be likely to provide symptom relief.

Where death is imminent and artificial hydration and/or nutrition are already in use, it may be appropriate to withdraw them if it is considered that the burdens outweigh the possible benefits to the patient.

Where death is not imminent, it usually will be appropriate to provide artificial nutrition or hydration. However, circumstances may arise where you judge that a patient's condition is so severe, and the prognosis so poor that providing artificial nutrition or hydration may cause suffering, or be too burdensome in relation to the possible benefits. In these circumstances, as well as consulting the health care team and those close to the patient, you must seek a second or expert opinion from a senior clinician (who might be from another discipline such as nursing) who has experience of the patient's condition and who is not already directly involved in the patient's care. This will ensure that, in a decision of such sensitivity, the patient's interests have been thoroughly considered, and will provide necessary reassurance to those close to the patient and to the wider public.

It can be extremely difficult to estimate how long a patient will live²³, especially for patients with multiple underlying conditions. Expert help in this should be sought where you, or the health care team, are uncertain about a particular patient.

82. Where significant conflicts arise about whether artificial nutrition or hydration should be provided, either between you and other members of the health care team or between the team and those close to the patient, and the disagreement cannot be resolved after informal or independent review, you should seek legal advice on whether it is necessary to apply to the court for a ruling.

83. Where you are considering withdrawing artificial nutrition and hydration from a patient in a permanent vegetative state (PVS), or condition closely resembling PVS, the courts in England, Wales and Northern Ireland currently require that you approach them for a ruling. The courts in Scotland have not specified such a requirement, but you should seek legal advice on whether a court declaration may be necessary in an individual case. (For leading cases see the legal summary at Appendix A).

Cardiopulmonary resuscitation

84. Cardiopulmonary resuscitation (CPR), if attempted promptly in appropriate situations, may be effective in restarting the heart and lungs of some patients. However CPR is known to have a low success rate, especially for patients with serious conditions who are in poor general health. CPR carries some risk of complications and harmful side effects, and if used inappropriately it may do more harm than good by prolonging the dying process and the pain or suffering of a seriously ill patient, in a manner which could be seen as degrading and undignified. For example, if a patient is at the end-stage of an incurable illness and death is imminent, attempts to resuscitate them are likely to be futile and not in the patient's best interests.

85. Advice on when it is appropriate to attempt to resuscitate a patient, and circumstances when it is appropriate to make an advance decision not to attempt resuscitation (DNAR order), is available from professional bodies²⁴.

86. Where a patient is already seriously ill with a foreseeable risk of cardiopulmonary arrest, or a patient is in poor general health and nearing the end of their life, decisions about whether to attempt CPR in particular circumstances ideally should be made in advance as part of the care plan for that patient. A patient's own views, about whether the level of burden or risk outweighs the likely benefits from successful CPR, would be central in deciding whether CPR should be attempted. It is important in these cases to offer competent patients or, if a patient lacks capacity to decide, those close to the patient, an early opportunity to discuss their future care and the circumstances in which CPR should or should not be attempted.

87. Discussions about circumstances in which CPR should not be attempted can be difficult and distressing for all concerned. However, failing to give patients or, where appropriate, those close to the patient, the opportunity to be involved in reaching a decision can cause more distress at a later stage, when the patient or a relative discovers a DNAR order was made, than if the issue were tackled sensitively at the outset.

88. Some patients may not wish to be given the details or to make decisions about CPR themselves. The wishes of these patients should be followed. Many patients - including some for whom CPR is likely to be futile - will want to be involved in the decision, and you must provide these patients with appropriate information about CPR²⁵, including up to date details about its effectiveness and appropriate use, to ensure a sufficient understanding of what is involved. There may be other patients for whom cardiopulmonary arrest is not a foreseeable risk who nevertheless raise the issue. You should respond honestly to their questions.

89. You should always take the patient's wishes into account. You must respect a competent patient's decision to refuse CPR. You should usually comply with patients' requests to provide CPR, although there is no obligation to provide treatment that you consider futile. The patient's decision must be recorded appropriately and communicated clearly to the health care team.

90. Where patients lack capacity to make a decision about CPR, you should consult the health care team, the patient's proxy decision maker - in Scotland, where appointed - or others close to the patient, taking account of any request made by the patient when competent not to discuss their care with particular individuals. Where, after appropriate consultation, it is your considered judgement that attempting CPR would not be in the patient's best interests, the reasons for that decision should be explained clearly to those consulted.

91. In holding discussions about CPR, you should make clear to the patient, the health care team and others consulted about the patient's care, that the provision of all other appropriate treatment and care would be unaffected by a decision not to attempt CPR.

92. Whilst the final decision about the clinical merits of attempting resuscitation rests with the consultant or general practitioner in charge of the patient's care, good consistent communication between the doctor, nurses, patient and carers is the key to ensuring that the patient's rights are respected, and misunderstanding and dissent are minimised.

93. Once a decision is made, you or a senior medical member of the team should record fully any advance decision not to attempt to resuscitate a patient, including the basis on which the decision was reached and the names of those with whom it was discussed. You should ensure that the decision is communicated to all those involved in providing care to the patient. A DNAR order should be reviewed regularly to ensure it remains appropriate in the patient's present condition.

94. In putting this guidance into practice, you should take account of relevant guidance from professional bodies²⁶, and relevant protocols²⁷ within the healthcare setting in which you work.

Accountability

95. If you decide not to follow any part of 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.

Appendix A: The legal background

This is not intended as a definitive statement of the law in this area. It is a summary of our understanding of the key points.

Case law

1. Doctors have a duty to protect the life and further the health of patients. 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 case law identifies some circumstances where withholding or withdrawing a life-prolonging treatment would be lawful, and establishes the following principles (see endnotes for case references):

- An act where the doctor's primary intentionⁱ is to bring about a patient's death would be unlawfulⁱⁱ.
- Withholding or withdrawing treatment is regarded in law as an 'omission' not an 'act'.
- A competent adult patient may decide to refuse treatment even where refusal may result in harm to themselves or in their own deathⁱⁱⁱ. 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^{iv}. Doctors are bound to respect a competent refusal of treatment and, where they have an objection to the decision, they have a duty to find another doctor who will carry out the patient's wishes^v.
- Life prolonging treatment may lawfully be withheld or withdrawn from incompetent patients when commencing or continuing treatment is not in their best interests^{vi}.
- There is no obligation to give treatment that is futile and burdensome^{vii}.
- Where an adult patient has become incompetent, a refusal of treatment made when the patient was competent must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had changed his/her mind^{viii}.
- For children or adults who lack capacity to decide, in reaching a view on whether a particular treatment would be more burdensome than beneficial, assessments of the likely quality of life for the patient with or without the particular treatment may be one of the appropriate considerations^{ix}.
- In the case of patients in a permanent vegetative state (PVS), artificial nutrition and hydration constitute medical treatment and may be lawfully withdrawn in certain circumstances^{x 28}. However, in practice, a court declaration should be obtained^{xi}.
- Final responsibility rests with the doctor to decide what treatments are clinically indicated and should be provided to the patient, subject to a competent patient's consent or, in the case of an incompetent patient, any known views of that patient prior to becoming incapacitated and taking account of the views offered by those close to the patient^{xii}.

Courts' approach to decision making

2. Case law also suggests that:

- Where a patient's capacity to consent to or refuse a treatment remains in doubt after appropriate steps have been taken to assess their capacity, or where differences of opinion about a patient's best interests cannot be resolved satisfactorily, legal advice should be sought about applying to the courts for a ruling.
- When the Court is asked to reach a view on whether it is in an incompetent patient's best interests to withhold or withdraw a treatment, it will have regard to whether what is proposed is in accordance with a responsible body of medical opinion. But the Court will determine for itself whether treatment or non-treatment is in the patient's best interests^{xiii}.

Legal developments

3. It is also important to note that the Human Rights Act 1998 may have implications for this area of medical decision making by incorporating into English law the [European Convention on Human Rights](#). Notably under that Convention, 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 clearer. At present the case law confirms that the existing common law principles are consistent with the European Convention on Human Rights^{xiv}. It is also clear that doctors' decisions are likely to be subject to greater scrutiny and the decision making process will need to be open, transparent and justifiable.

4. 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.

i R v Cox (1992) 12 BMLR 38.

ii For a very rare exception in the case of conjoined twins see Re: A (Children) (Conjoined twins: surgical separation) [2000] 4 All ER 961.

iii Airedale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48 and Re AK (Medical Treatment: Consent) [2001] 1 FLR 129.

iv St George's Healthcare Trust v S (No 2). R v Louise Collins & Others, Ex Parte S (No 2) [1993] 3 WLR 936.

v Re Ms B v a NHS Hospital Trust [2002] EWHC 429 (Fam).

vi Airedale NHS Trust v Bland [1993] 1 All ER 821.

vii Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.

viii Airedale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Also Re T (Adult: Refusal of Treatment) [1992] 4 All ER 349 and Re AK (Medical Treatment: Consent) [2001] 1 FLR 129.

ix Re B [1981] 1 WLR 421; Re C (A Minor) [1989] All ER 782; Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930; Re R (Adult: Medical Treatment) [1996] 2 FLR 99.

x Airedale NHS Trust v Bland [1993] 1 All ER 821; Law Hospital NHS Trust v Lord Advocate 1996 SLT 848.

xi Airedale NHS Trust v Bland [1993] 1 All ER 821; Law Hospital NHS Trust v Lord Advocate 1996 SLT 848. Also refer to Practice Note (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults Who Lack Capacity) [2001] 2 FLR.

xii Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614; and Re G (Persistent Vegetative State) [1995] 2 FCR 46.

xiii Re A (Male Sterilisation) [2000] FCR 193; and Re S (Adult: Sterilisation) [2000] 2 FLR 389.

xiv A National Health Trust v D (2000) 55 BMLR 19; NHS Trust A v M and NHS Trust B v H (2000) 58 BMLR 87.

Appendix B Glossary

This defines some key 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 adults at a time they have capacity to decide for themselves about the treatments they wish to accept or refuse, in circumstances in the future where they are no longer able to make decisions or communicate their preferences. An advance statement cannot authorise a doctor to do anything that is illegal. Where a specific treatment is requested, doctors are not bound to provide it, if in their professional view it is clinically inappropriate. An advance refusal of treatment made when an adult patient was competent, on the basis of adequate information about the implications of his/her choice, is legally binding and must be respected where it is clearly applicable to the patient's present circumstances and where there is no reason to believe that the patient had changed his/her mind.

Artificial nutrition and hydration

This term is commonly used in medicine to refer to techniques such as the use of nasogastric tubes, percutaneous endoscopic gastrostomy ('gastric PEG'), subcutaneous hydration, or intravenous cannula, to provide a patient with nutrition and hydration where a patient has a problem taking fluids or food orally. A distinction is generally made between such 'artificial' means and 'oral' nutrition and hydration where food or drink is given by mouth, the latter being regarded as part of nursing care.

Nursing care

Sometimes also referred to as 'basic care' there is no legal or commonly accepted definition of what is covered by this term. In the medical profession it is most often used to refer to procedures or medications which are solely or primarily aimed at providing comfort to a patient or alleviating that person's pain, symptoms or distress. It includes the offer of oral nutrition and hydration.

Proxy decision maker

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 under provisions in the Adults with Incapacity (Scotland) Act 2000 a welfare attorney, welfare guardian or a person authorised under an intervention order, may be granted authority to make medical decisions on behalf of an adult patient with incapacity. These persons can be referred to as proxy decision-makers. ('Proxy decision maker' is not an accepted legal term in England and Wales). There is a Code of Practice under the Act for making decisions on behalf of adults with incapacity. Advice on the powers of welfare attorneys, welfare guardians or a person authorised under an intervention order, and on the Code of Practice can be obtained from medical defence bodies, the Scottish Executive, Health Department and the BMA.

'Those close to the patient'

This phrase is intended to include any of the following - a professional or other carer, a partner, a close family member, an informal advocate. It will also include, in Scotland, any proxy decision maker appointed under the Adults with Incapacity (Scotland) Act 2000, and a 'nearest relative' or 'person claiming an interest' - such as a public guardian, mental welfare commissioner, local authority - as referred to in this Act or under the provisions of Scottish mental health legislation. In England and Wales under mental health legislation, a 'nearest relative' or 'guardian' may have been appointed.

Starting then stopping treatment

Some people find it difficult to contemplate withdrawing a life-prolonging treatment once started, either because of the emotional distress that can accompany such a decision, or because they have concerns about what might be seen as their 'responsibility' for the patient's death. This sense of responsibility may particularly arise for those who understand withdrawing treatment as a positive 'act' which is morally more blameworthy than not starting treatment. (An example often given is the position held by some within the Jewish faith who make this distinction.) However, within the current broad consensus about ethical practice in medicine and taking account of the legal position, there is no ethical or legal obligation to continue to provide a treatment where it has been decided that the treatment is not in the best interests of the patient.

Footnotes

1 See [glossary definition](#).

2 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 vulnerable, and to ensure that doctors only take these decisions after appropriate consultation.

3 A patient will be competent if he or she can: comprehend information, it having been presented to them in a clear way; believe it; and retain it long enough to weigh it up and make a decision. From *Re C (Adult: Refusal of Medical Treatment)* [1994] All ER 819.

4 Note the provisions of the Mental Health Act 1983, Mental Health (Scotland) Act 1984, and Mental Health (Northern Ireland) Order 1986 that permit compulsory treatment of detained patients for their mental disorder in certain circumstances.

5 See the section on the legal background - paragraph 2 and endnote (ii) case references.

6 'Those close to the patient' may include a professional or other carer, partner, close family member, advocate, and in Scotland a proxy decision maker appointed under the Adults with Incapacity (Scotland) Act 2000. See the glossary for more details.

7 The Adults with Incapacity (Scotland) Act 2000 establishes a statutory general authority to treat where a certificate of incapacity has been issued, and also provides for a welfare attorney, welfare guardian, or person authorised under an intervention order to be granted power to make decisions on behalf of a patient. Doctors practising in Scotland should seek legal advice on the Act and its related Codes of Practice.

8 For more background on these concerns see the glossary under 'starting then stopping treatment'.

9 'Nursing care' is defined in the glossary.

10 See the glossary for a definition of what is termed 'artificial' nutrition and hydration.

11 For advice on issues which patients may want to explore consult publications like 'The Future of Health and Care of Older People', Age Concern, 2000. And 'Feeling Better: Psychosocial Care in Specialist Palliative Care'. National Council for Hospices and Specialist Palliative Care Services, August 1997.

12 For further advice on management and aftercare issues consult publications like 'Withholding and Withdrawing Life-Prolonging Medical Treatment: Guidance for decision making', BMA London, 2nd edition 2001. Managing Terminal Illness Royal College of Physicians of London, 1996. 'Changing Gear: Managing the Last Days of Life', National Council for Hospices and Specialist Palliative Care Services, December 1997.

13 Advice on effective communication with patients can be found in publications such as ['Consent: patients and doctors making decisions together'](#) 'Breaking Bad News' Royal College of Physicians, 1998.

14 For example 'Assessment of Mental Capacity: Guidance for Doctors and Lawyers'. The Law Society/BMA, 1995.

15 See Re C (Adult: Refusal of Medical Treatment) [1994] 1 All ER 819. Also the Adults with Incapacity (Scotland) Act 2000 establishes a statutory test of capacity.

16 Some hospitals and NHS Trusts have clinical ethics committees or other arrangements for access to clinical ethics support and advice. Where such arrangements are not available locally, advice of this kind can be accessed through a number of sources. Useful starting points will be the British Medical Association especially through its Ethics Department at BMA House, Tavistock Square, London. Telephone 020 7383 6286. Also the National Network of Clinical Ethics Committees which can be contacted through ETHOX, Institute of Health Sciences, Old Road, Oxford OX3 7LF. Telephone 01865 226849.

17 Up to date legal advice is available from sources such as medical defence bodies, employers' solicitors. You may find it helpful to consult publications such as 'Consent, rights and choices in health care for children and young people.' British Medical Association, London, December 2001. Available from BMJ Bookshop, Burton Street London WC1H 9JR.

18 Age of Legal Capacity (Scotland) Act 1991 (Section 2.4); Gillick v West Norfolk and Wisbech AHA [1985].

19 Re W (a minor) [1992] 4 All ER 627.

20 Examples of advice on handling discussions are: 'Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice', Royal College of Paediatrics and

Child Health, London 1997. 'Withdrawing Treatment from Infants. Key Elements in the Support of Families', McHaffie, H.E. (2001) Journal of Neonatal Nursing 7(3): 85-89.

21 Published advice is available from a number of sources. For example, '[Ethical Decision-Making in Palliative Care: Artificial Hydration for People who are Terminally Ill](#)', Ethics Working Party, August 1997, National Council for Hospices and Specialist Palliative Care Services.

22 For example, there is published advice in the 'Oxford Textbook of Palliative Medicine' ed. Doyle, Hanks, MacDonald.

23 For example see 'Accuracy of prognosis estimates by four palliative care teams: a prospective cohort study.' Higginson IJ, Costantini M. BMC Palliative Care 2002; 1: 1.

24 For example, '[CPR guidance for clinical practice and training in hospitals](#)' February 2000 and '[CPR guidance for clinical practice and training in primary care](#)' July 2001 from the Resuscitation Council (UK). London.

25 For example, the BMA's model information leaflet for patients: 'Decisions about cardiopulmonary resuscitation' BMA 2002, available from BMA House, Tavistock Square, London WC1H 9JP or browse at <http://www.bma.org.uk>

26 'Decisions Relating to Cardiopulmonary Resuscitation: A joint statement by the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing' BMA, London, February 2001, available from BMA House, Tavistock Square, London WC1H 9JP or browse at <http://www.bma.org.uk>.

27 For example, NHSE '[Resuscitation Policy](#)' (pdf) HSC 2000/028. Department of Health, London, September 2000. Scottish Executive Health Department. '[Resuscitation Policy](#)' (pdf) HDL (2000) 22, Scottish Executive, November 2000.

28 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' Journal of the Royal College of Physicians of London. (1996) vol 30 (2) 119-121.

Withdrawn