

General
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Regulating doctors
Ensuring good medical practice

***End of life treatment and care:
Good practice in decision-making***

A draft for consultation

End of life treatment and care: Good practice in decision-making

	Paragraphs
About the guidance	1-5
How the guidance applies to you	6-8
Introduction	9-12
Principles and decision-making framework	13-19
<i>Equalities and human rights</i>	13-15
<i>Presumption in favour of prolonging life</i>	16
<i>Decision-making framework</i>	17-19
Patients with capacity	17
Patients without capacity	18
Applying the principles in practice	20-73
<i>Making sound clinical judgements</i>	21-24
<i>Explaining the clinical issues</i>	25-27
<i>Addressing uncertainty</i>	28-29
<i>Emotional difficulties in end of life decision-making</i>	30-32
<i>Resource constraints</i>	33-35
<i>Assessing the overall benefits of treatment options</i>	36-42
<i>Advance care planning</i>	43-53
Making advance requests for treatment	51-52
Making advance refusals of treatment	53
<i>Acting on advance requests for and refusals of treatment</i>	54-61
<i>Recording and communicating decisions</i>	62-65

<i>Reviewing decisions</i>	66
<i>Conscientious objections</i>	67
<i>Care after death</i>	68-70
Organ donation	71-72
<i>Audit of practice</i>	73
Neonates, children and young people	74-82
Special challenges in applying the guidance	83-112
<i>Clinically assisted nutrition and hydration</i>	83-97
Patients with capacity	89
Patients without capacity	90-94
All patients	95-97
<i>Cardiopulmonary resuscitation</i>	98-112
Discussions where CPR will not be successful	102-104
Discussions where CPR may be successful	105-109
Treatment and care after a CPR decision	110-111
Emergencies and CPR	112
<i>Legal Annex</i>	

End of life treatment and care: Good practice in decision-making

About the guidance

1. Good end of life care helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity. This guidance is intended to support doctors' decision-making and help them to provide patients with high quality end of life care, including involvement of and support for those close to the patient (family members, carers and others who have an interest in their welfare). Providing this care means facing decisions which may be clinically complex and emotionally distressing and the guidance explores how doctors can address these issues.

2. This guidance replaces the booklet *Withholding and Withdrawing Life-Prolonging Treatments* (2002). It expands on the principles of good practice in our guidance *Good Medical Practice* (2006) and *Consent: patients and doctors making decisions together* (2008), to set out the approach which doctors should take to the particular challenges that arise in providing care towards the end of life. [All our guidance documents can be read on our website through links from the online version of this publication.]

3. This 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 the care of their patients their first concern.

4. This guidance also takes account of, and is consistent with, current law across the UK, in particular the law prohibiting killing (including euthanasia) and assisted suicide and the requirements of the Human Rights Act 1998. Annex A contains references to relevant case law and legislation. However it is not intended as a substitute for up to date legal advice in individual cases. The law differs across the UK and it is important that doctors seek up to date legal advice, wherever there is uncertainty about how a particular decision might be viewed in law.

5. This guidance is addressed to doctors. However, it may help patients and the public understand what to expect of their doctors, in circumstances where patients and those close to them may be particularly vulnerable and in need of support. Members of the healthcare team may also benefit from this guidance, given their crucial role in delivering end of life care.

How the guidance applies to you

6. In this guidance the terms 'you must' and 'you should' are used in the following ways.

- 'you must' is used for an overriding duty or principle
- 'you should' is used when we are providing an explanation of how you will meet the overriding duty
- 'you should' is also used where the duty or principle will not apply in all situations or circumstances, or where there are factors outside your control that affect whether or how you can comply with the guidance.

7. The guidance is not, and cannot be, exhaustive. So you should use your own judgement to apply the principles it sets out to the situations you face in your own practice.

8. Serious or persistent failure to follow this guidance will put your registration at risk. You must, therefore, be prepared to explain and justify your actions.

Introduction

9. Good end of life care helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity. For the purpose of this guidance, the term 'life-limiting conditions' includes:

- a. Organ or systems failure, where patients are likely to die suddenly as a result of an acute crisis (for example heart failure, chronic respiratory disease).
- b. Life threatening acute conditions caused by sudden catastrophic events (for example brain damage from head injury).
- c. Progressive conditions such as cancer and dementia.
- d. Permanent vegetative state (PVS) and conditions closely resembling this, which cause an irrevocable loss of awareness.

This guidance applies to all patients with life-limiting conditions, including extremely premature neonates, children and young people.

10. End of life care encompasses palliative care, which focuses on managing pain and other distressing symptoms, providing psychological, social and spiritual support to patients, and supporting those close to the patient. Palliative care can be provided at any stage in the progression of a patient's illness, not only in the last days of a patient's life when the focus of treatment has generally moved from trying to actively manage disease and prevent deterioration to managing the patient's symptoms and keeping them comfortable.

11. The most difficult and sensitive decisions in end of life care are often those around starting, or stopping, potentially life-prolonging treatments such as cardiopulmonary resuscitation (CPR), renal dialysis, 'artificial' nutrition and hydration

(for the purpose of this guidance 'artificial' is replaced by 'clinically assisted'¹) and mechanical ventilation. These treatments have many potential benefits including extending the lives of patients who otherwise might die from their underlying condition. But in some circumstances they may only prolong the dying process or cause the patient unnecessary distress. The benefits, burdens and risks of these treatments are not always well understood and concerns can arise about over- or under- treatment, particularly where there is uncertainty about the clinical effect of a treatment on the individual patient, or about how the benefits and burdens for that patient are being assessed. Doctors and others involved in the decision-making process may also be unclear about what is legally and ethically permissible, especially in relation to decisions to stop a potentially life-prolonging treatment.

12. The framework for decision-making in end of life care is essentially the same as for any other phase of clinical care. The principles of good decision-making are set out in *Consent: patients and doctors making decisions together*, which also provides advice about how to communicate effectively, and work towards achieving a consensus, with patients and those close to them and within the healthcare team. This guidance expands on *Consent*, explaining how the principles apply to specific issues that arise in relation to end of life care, which doctors, patients and others involved in making decisions can find difficult to address.

Principles and decision-making framework

Equalities and human rights

13. All patients have the right to be treated with dignity and respect throughout the course of their care. Patients who are dying must receive the same standard of care as all other patients. Their privacy and dignity must be respected and good quality

¹ 'Artificial' nutrition and hydration is the descriptive phrase in current use. However 'clinically assisted' is a more accurate description of techniques such as use of a drip, a naso-gastric tube or a tube surgically implanted into the stomach, to provide nutrition and fluids.

care provided in comfortable surroundings. Patients and those close to them must be treated with understanding and compassion.

14. Some patients (such as older people, those with disabilities, or from ethnic minorities) experience problems in accessing good quality care, and this may have serious consequences when they are in need of end of life treatment and care. Equalities, capacity and human rights laws reinforce the ethical duty on doctors to ensure that all patients receive the same standard of care.

15. Decisions about treatment and care towards the end of life are likely to engage the basic rights and principles set out in the Human Rights Act 1998. It is important that all doctors are aware of the Act and are familiar with its principles. Doctors providing NHS services must be able to demonstrate that their decisions are consistent with its terms². Human rights requirements reflect very closely the established ethical principles and obligations that underpin decisions about medical treatment.

Presumption in favour of prolonging life

16. Decisions concerning life-prolonging treatment must not be motivated by a desire to bring about the patient's death, and must start from a presumption in favour of prolonging life. However, there is no absolute obligation to prolong life irrespective of the consequences for the patient and such decisions must take account of the patient's views where these are known or can be ascertained. Ethical, legal and human rights principles place an obligation on doctors to offer patients those treatments where the possible benefits outweigh any burdens or risks associated with the treatment; and to avoid those treatments which will not work, or provide no overall benefit to a patient, or have been refused by a patient with capacity.

² The legal annex provides an explanation of the European Convention rights which are incorporated into the Act and which are most relevant to end of life decisions.

Decision-making framework

Patients with capacity

17. Where patients have capacity to make decisions for themselves:
 - a. The doctor and patient make an assessment of the patient's condition, taking into account the patient's medical history, views, experience and knowledge.
 - b. The doctor uses specialist knowledge and experience and clinical judgment, and the patient's views and understanding of their condition, to identify which investigations or treatments are likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, risks, burdens and side effects of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice.
 - c. The patient weighs up the potential benefits, risks and burdens of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which one. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.
 - d. If the patient asks for a treatment that the doctor considers would not be of overall benefit to them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after discussion, the doctor still considers that the treatment would not be of overall benefit to the patient, they do not have to provide the treatment. But they should explain their reasons to the patient, and explain any other options that are available, including the option to seek a second opinion.

Patients without capacity

18. Where patients lack or have impaired capacity to make decisions for themselves, doctors must:

- a. Support and encourage the patient to be involved in decisions, as far as they want and are able, and take account of their wishes, feelings, beliefs and values (even if they lack capacity to make the particular decision themselves).
- b. Consider whether the patient's lack of capacity is temporary, fluctuating or permanent.
- c. Consider which options (including non-treatment) would be least restrictive of the patient's future choices.
- d. Take into account any evidence of the patient's previously expressed wishes, such as an advance statement, decision or directive.
- e. Seek agreement from anyone who has legal authority to make the decision on their behalf³ and consult with anyone who has been appointed to represent the patient⁴.
- f. Work with those close to the patient and members of the healthcare team, to explore their views about the patient's preferences, feelings, beliefs and values and whether they consider the proposed course of action would be of overall benefit⁵ to the patient.
- g. Follow the law and codes of practice on decision-making with patients who lack capacity to make their own decisions. This may include, for some

³ For a child: those who hold parental responsibility. For adults: holders of Lasting Power of Attorney and court-appointed Deputies (England & Wales); holders of Welfare Power of Attorney and court-appointed Guardians and intervenors (Scotland).

⁴ Independent Mental Capacity Advocates (England and Wales). Independent advocates (Scotland).

⁵ The term 'overall benefit' is used to encompass the legal concepts of 'best interests' (as used in England, Wales and Northern Ireland) and 'benefit' weighed with other factors relevant to the patient (as used in Scotland).

patients in England and Wales, a need to appoint an Independent Mental Capacity Advocate to represent the patient's interests.

19. *Consent: patients and doctors making decisions together* contains specific guidance on:

- a. Supporting patients to participate in decision-making and assessing their capacity.
- b. Helpful approaches to achieve clear, effective and sensitive communication with patients and those close to them.
- c. The advisory roles of family, informal and paid carers.
- d. The role of people with legal authority to make healthcare decisions on a patient's behalf.

Applying the principles in practice

20. This section provides advice on applying the general principles and the decision-making framework in practice.

Making sound clinical judgements

21. The starting point for reaching good decisions is careful consideration of the individual patient's clinical situation. You must carry out a thorough review of the patient's condition and assess the likely prognosis. It can be extremely difficult to estimate how long a patient will live⁶, and you should seek expert help in making this assessment where you, or the healthcare team, are uncertain about the prognosis of a particular patient.

22. You should also give early consideration to the patient's palliative care needs, and consider how to manage any pain, breathlessness, agitation or other distressing

⁶ The 'Prognostic Indicator Guidance Paper' in the Gold Standards Framework. Available at www.goldstandardsframework.nhs.uk and www.gsfs.scot.nhs.uk.

symptoms⁷ that they may be experiencing. If you are uncertain about how to manage a patient's symptoms effectively, you should seek and follow advice from a specialist palliative care clinician. You must not leave the patient in avoidable pain or discomfort.

23. You should identify treatment options based on:
 - a. Up to date clinical evidence about effectiveness, side effects and other risks.
 - b. Relevant clinical guidelines on the treatment and management of the patient's condition, or of patients with similar underlying risk factors, such as those issued by the National Institute for Health and Clinical Excellence (NICE) and the Scottish Intercollegiate Guidelines Network (SIGN).
24. You should consult a colleague with relevant experience (who may be from another speciality, such as palliative care, or another discipline, such as nursing) if:
 - a. You and the healthcare team have limited experience of a condition.
 - b. You are in doubt about the range of options, or the benefits, burdens and risks of a particular option for the individual patient.
 - c. There is a serious difference of opinion within the healthcare team, or between the team and those close to the patient, about your preferred option for a patient's treatment and care.

Explaining the clinical issues

25. You should explore treatment options with patients (and, where appropriate, with those close to them) focusing on the goals of care, and explain the likely benefits, burdens and risks. You should bear in mind that patients and those close to

⁷ *Changing Gear – guidelines for managing the last days of life in adults* (Nov 2006). National Council for Palliative Care. *Control of Pain in Adults with Cancer*. Guideline 106 (Nov 2008). Scottish Intercollegiate Guideline Network. *Principles of Pain Control in Palliative Care for Adults*. Working Party report, Royal College of Physicians of London.

them may not always have a clear or realistic understanding of the benefits, burdens and risks of a treatment option. This is particularly the case in respect of treatments such as CPR and clinically assisted nutrition and hydration where the public's knowledge about the clinical complexities may be limited.

26. Patients and those close to them may also draw unintended conclusions from the terminology used by healthcare staff about the risks or expected outcomes of these treatments. You should explain the treatment options in a way that they can understand, explaining any medical or other technical terminology that you use.

27. You should be open about the clinical issues including any underlying uncertainties, as this helps to build trust and reduce the scope for later conflict. You should refer to *Consent: patients and doctors making decisions together* (paragraphs 7-12, 18-25, 28 -36) which gives specific advice on how to communicate clearly and effectively with those close to the patient or others with an interest in their welfare, especially when explaining the side effects or other risks associated with treatments.

Addressing uncertainty

28. Where there is a reasonable degree of uncertainty about whether a particular treatment will be of overall benefit, and the patient lacks capacity to make the decision, the treatment should be started to allow a clearer assessment to be made with additional time and consultation with other clinicians. Uncertainty of this kind might arise, for example, in an emergency, an acute crisis in a patient's care, and in cases where there is only a small chance of success and doubts arise about whether the benefits of treatment outweigh the associated burdens.

29. You must explain clearly to those close to the patient and the healthcare team that the treatment will be reviewed, and may be stopped at a later stage, if it proves ineffective or too burdensome for the patient in relation to the benefits. You should agree at the outset how long the treatment will be tried and the basis on which the decision will be made about whether it will continue or be stopped.

Emotional difficulties in end-of-life decision-making

30. Some members of the healthcare team, or people who are close to the patient, may find it more difficult to contemplate stopping a life-prolonging treatment, than deciding not to start the treatment in the first place. This may be because of the emotional distress that can accompany a decision to stop life-prolonging treatment, or because they feel responsible for the patient's death. This sense of responsibility may arise particularly for those people who view stopping treatment as an action which is morally different from not starting treatment. However, you should not allow these anxieties to override your clinical judgment and lead you either to withhold treatment that may be of some benefit to the patient, or to continue treatment that is of no overall benefit.

31. You should explain to those close to the patient that, whatever decisions are made about providing particular treatments, the patient's condition will be monitored and managed to ensure that they are comfortable and, as far as possible, free of pain and other distressing symptoms. You should also make clear that a decision to stop, or not to start a treatment will be reviewed if the patient's condition improves unexpectedly.

32. You should offer advice about any support that may be available to the patient, those close to them and members of the healthcare team, where they are finding the situation emotionally challenging⁸. You should do your best to ensure that vulnerable patients, who may feel pressured by family or carers to accept or refuse particular investigations or treatments, receive the help they need to reach their own decisions.

Resource constraints

33. Decisions about what treatment options can be offered may be complicated by resource constraints – for example, funding restrictions on certain treatments in the NHS, or lack of availability of intensive care beds. In such circumstances, you

⁸ Patient and carer support and advocacy services; counselling and chaplaincy services; ethics support networks. See the advice and resources available at www.endoflifecareforadults.nhs.uk

must balance sometimes competing duties towards the individual patient, the wider population, funding bodies and employers. There will often be no simple solution and, ideally, decisions about access to treatments should be made on the basis of an agreed local or national policy⁹, which takes account of the human rights implications. Decisions made on a case-by-case basis, without reference to agreed policy, risk introducing elements of unfair discrimination or failure to properly consider the patient's human rights (see paragraph 14).

34. Where resource constraints are a factor, you must:
- a. Provide the best service possible within the resources available.
 - b. Be familiar with any local and national policies which set out agreed criteria for access to the particular treatment (such as national service frameworks and NICE/SIGN guidelines).
 - c. Give priority to patients on the basis of need, where you are able to do so, considering the overall benefit that treatment offers to the patient.
 - d. Be fair and non-discriminatory in decisions about prioritising patients.
 - e. Be open and honest about the decision-making process and the criteria for prioritising patients in individual cases.
35. You should make every effort to avoid withholding or stopping treatment when this would involve significant risk for the patient and the only justification for doing so is resource limitation. If you have good reason to think that patient safety is being compromised by inadequate resources, and it is not within your power to put the matter right, you should draw the situation to the attention of the appropriate individual or organisation, following our supplementary guidance on *Raising concerns about patient safety (2006)*.

⁹ *Supporting rational decision-making about medicines (and treatments). A handbook of good practice.* First edition. Feb 2009. NHS National Prescribing Centre.

Assessing the overall benefits of treatment options

36. The presumption in favour of prolonging life will normally require you to take all reasonable steps to prolong a patient's life. However, as raised in paragraph 16, there are circumstances where it may be appropriate not to start or continue with potentially life-prolonging treatment.

37. You must not start or continue with a potentially life-prolonging treatment if the patient with capacity has refused it, and should not normally do so where the patient lacks capacity to decide and it is agreed that treatment would not be of overall benefit to them. It may also be of no overall benefit to provide potentially life-prolonging treatments in the last days of a patient's life when the focus of care is changing from active treatment to palliation of symptoms and relief of the patient's suffering.

38. The benefits and burdens associated with a treatment are not always limited to clinical considerations, and you should be careful to take account of the other factors relevant to the circumstances of each patient (as set out in the framework at paragraphs 17-18). Additionally, in the case of a patient who lacks capacity, you should follow current law and related codes of practice which set out the factors to be considered in determining what would be of overall benefit for the patient¹⁰.

39. Some patients, and those close to them, may not be aware of the range of services and treatments available to them, and this could have a bearing on the options they would see as offering most benefit. You should satisfy yourself that patients have sufficient information and support so that their rights and interests are being properly addressed in the decision-making process.

40. It may be particularly difficult to arrive at a view about whether a treatment would be of overall benefit, where patients have problems in communicating their wishes and preferences, or lack capacity to decide for themselves. In such cases you must not simply substitute your own values or those of the people consulted

¹⁰ Mental Capacity Act Code of Practice, Chapter 5; Adults with Incapacity (Scotland) Act Part 5 Code of Practice, Chapter 2.

about the patient. You should refer to the advice in *Consent: patients and doctors making decisions together* about meeting patients' information needs; the use of independent advocates; and other ways of maximising a patient's ability to participate in the decision making process.

41. You must be careful not to rely on your personal views about a patient's quality of life or make judgements based on poorly informed or negative views about the healthcare needs of particular groups, such as older people and those with disabilities¹¹.

42. You should aim to reach a consensus about what treatment and care would be of overall benefit to the patient. If disagreements arise, either between those close to a patient and the healthcare team, or between you and other members of the healthcare team, and they cannot be resolved through informal processes or independent review (*Consent: patients and doctors making decisions together* paragraph 77), you must seek legal advice about applying to the appropriate court or statutory body for a ruling. You should alert, as early as possible, the patient or those acting for them and those with an interest in their welfare, so that they have the opportunity to participate or be represented.

Advance care planning

43. The emotional distress and other pressures inherent in situations where patients are approaching the end of their life sometimes cause misunderstandings and conflict between doctors, patients and those close to them, or between members of the healthcare team. However, this can usually be avoided where there has been early sensitive discussion and planning about how best to manage the patient's care.

44. End of life treatment and care is delivered by multi-disciplinary, multi-professional teams and across local health, social care and voluntary sector services. To ensure timely access to safe, effective care and continuity in its delivery,

¹¹ 'Equal treatment: closing the gap. Information for practitioners.' (2006) DRC and *Supplement to Good Medical Practice* (2007) DRC. Available from the Equality and Human Rights Commission.

it is important to plan ahead as much as possible to meet patients' individual needs¹².

45. Patients whose death from their current condition is a foreseeable possibility are likely to want the opportunity to decide what arrangements should be made to manage the final stages of their illness, including access to palliative care, and to attend to any personal and other matters that they would consider important towards the end of their life.

46. Where a patient has a condition that will impair their capacity as it progresses (such as dementia or multiple sclerosis), or is otherwise facing a situation in which loss or impairment of capacity is a foreseeable possibility, you should encourage them to think about what they might want for themselves should this happen, and to discuss their wishes and concerns with you and the healthcare team. Your discussions should cover:

- a. The patient's wishes, preferences or fears in relation to their future treatment and care.
- b. The feelings, beliefs or values that may be influencing the patient's preferences and decisions.
- c. The family members, friends, carers or representatives that the patient would like to be involved in decisions about their care.
- d. Interventions which are likely to become necessary in an emergency, such as cardio-pulmonary resuscitation (CPR), where it may be helpful to make decisions in advance.

'Dying in older age: reflections and experiences from an older person's perspective.' (2005) Help the Aged.

¹² For example: *Joined up thinking. Joined up care. Increasing access to palliative care for people with life-threatening conditions other than cancer* (Nov 2006). Scottish Partnership for Palliative Care. *Opening doors: improving access to hospice and palliative care services by members of black and ethnic minority communities* (1995). National Council for Palliative Care, London.

e. The patient's preferred place of care (which may affect the treatment options available).

f. The patient's needs for religious, spiritual or other personal support.

47. You must approach such discussions sensitively. If you are unsure how best to do this or how to respond to any issues raised under (a) – (f), you should refer to guidelines on good practice in advance care planning¹³. If the patient agrees, you should consider involving other members of the healthcare team, people who are close to the patient or an independent advocate.

48. You should refer to paragraphs 13 – 17 of *Consent: patients and doctors making decisions together*, if a patient does not want to know in detail about their condition and treatment; asks you to make decisions for them; prefers to leave the decisions to a relative or another close person; or if a relative or carer asks you to withhold necessary information from the patient.

49. Where a patient wants to nominate someone to make decisions on their behalf if they lose capacity, or if they want to make an advance refusal of a particular treatment, you should explain that there may be ways to formalise these wishes (such as appointing an attorney or making a written advance decision or directive¹⁴). You should support patients who have decided to take these steps. You should provide advice on the clinical issues and recommend that they get independent advice on how to formalise their wishes.¹⁵

50. You should make a record of the discussion and of the decisions made. You should make sure that a record of the advance care plan is made available to the patient and others involved in their care, so that everyone is clear about what has

¹³ 'Advanced care planning: national guidelines.' Royal College of Physicians of London. February 2009. *Advance care planning: a guide for health and social care staff* (Aug 2008) - available at www.endoflifecareforadults.nhs.uk.

¹⁴ The MCA and AWISA legislation make provision for adults to grant powers of attorney to make healthcare decisions. The MCA sets out statutory requirements for making advance refusals of life-prolonging treatments. Northern Ireland proposes similar legislation. See the legal annex.

¹⁵ For doctors and patients: advice is available from www.adrtnhs.co.uk; the Office of the Public Guardian (England and Wales) www.publicguardian.gov.uk; and Mental Welfare Commission for Scotland www.mwcs.org.uk. Patient support organisations also provide advice.

been agreed (see also paragraphs 62-65). You should bear in mind that care plans need to be reviewed and updated as the situation or the patient's views change.

Making advance requests for treatment

51. In planning ahead, some patients worry that they will be unreasonably denied certain interventions towards the end of their life, and so they may wish to make an advance request for those treatments. Some patients who are approaching the last days of life may have specific reasons for wanting to receive a treatment which has some prospects of prolonging their life, even if only for a very short time. Some patients may hold strong views about receiving clinically assisted nutrition and hydration towards the end of their life, because they see these not as medical treatment but part of basic care.

52. In responding to requests for future treatment, you should explain how the patient's current wishes would be taken into account if they lose capacity to make decisions about their care, following the advice in paragraphs 54-55 of this guidance. As these concerns often arise in relation to clinically assisted nutrition and hydration and CPR, you should refer to paragraphs 93 and 108 which provide advice on responding to requests for these treatments.

Making advance refusals of treatment

53. Some patients worry about over-treatment towards the end of their life and they may want to make an advance decision or directive¹⁶ refusing particular treatments, in circumstances that might arise in the course of their future care. In discussing any proposed advance decision or directive (hereafter called 'advance refusals'), you should explain to patients how such decisions would be taken into account if they lose capacity to make decisions about their care. Guidance on how you should evaluate and act on advance refusals is given in paragraphs 56 - 61.

¹⁶ The MCA and AWISA legislation and Codes of Practice use different terminology in referring to advance refusals of treatment. The legal term in Scotland is 'advance directive' and for England and Wales it is 'advance decision'.

Acting on advance requests for and refusals of treatment

54. Where a patient who has lost capacity requested a particular treatment while they had capacity, you should be prepared to provide that treatment if you consider that it will prolong the patient's life or provide symptom relief. You should take into account the goals of care at this stage, and consult with the patient's representative and/or those close to the patient, to reach a view about whether the treatment will be of overall benefit.

55. Where death is imminent (within a few days or within hours), and the burdens of continuing a potentially life-prolonging treatment outweigh any possible benefits to the patient, it usually will be appropriate to stop the treatment, while focusing on meeting the patient's needs for palliative care and effective symptom management. However, if the patient had previously requested that the treatment be continued in these circumstances, you should consider any harm that might be caused, on the one hand by going against the patient's wishes and on the other by continuing to provide the treatment. If significant disagreement arises between you and the patient's representative or those close to them, or members of the healthcare team, about what would be of overall benefit to the patient, you must take steps to resolve this (see paragraphs 77-78 of *Consent: patients and doctors making decisions together* for guidance on resolving disagreements).

56. A valid advance refusal is one that was made when the patient had capacity to decide, on the basis of adequate information about the implications of his/her choice. A valid advance refusal must be respected, where it is clearly applicable to the patient's present circumstances and there is no reason to believe that they have changed their mind¹⁷.

57. If you are the clinician with lead responsibility for the patient's care, you should assess the validity and applicability of any advance refusal that is recorded in the notes, or otherwise brought to your attention. The factors you should consider

¹⁷ This is the position in Scotland, England and Wales, although the legal status of advance refusals differs slightly between these jurisdictions – refer to the MCA or AWISA Codes of Practice for details.

vary between the four UK countries, reflecting differences in the legal framework (see the legal annex). However, the main considerations are that:

- a. The patient was an adult when the decision was made (16 years old or over in Scotland, 18 years in England, Wales and Northern Ireland)
- b. The patient had capacity to make the decision at the time it was made (UK wide)
- c. The patient was not subject to undue influence in making the decision (UK wide)
- d. Where the decision relates to treatment that may prolong life; it must be in writing, signed and witnessed and include a statement that it is to apply even if the patient's life is at stake. (England and Wales only¹⁸)
- e. The decision has not been withdrawn by the patient (UK wide)
- f. The patient has not, since the decision was made, appointed an attorney to make such decisions on their behalf (England, Wales and Scotland)
- g. The decision is clearly applicable to the circumstances that have arisen (UK wide).
- h. Since the decision was made, the patient has not done anything which is clearly inconsistent with its terms (UK wide).

58. Advance refusals of treatment often do not come to light until a patient has lost capacity. In such cases, you should start from a presumption that the patient had capacity when the decision was made, unless there are grounds to suspect otherwise.

¹⁸ These requirements are set out in the MCA and its Code of Practice, Chapter 9.

59. In deciding whether the advance refusal of treatment is clearly applicable to the circumstances that have arisen, you should check whether the advance refusal specifies particular treatments or circumstances when the refusal should apply. You should consider how long ago the decision was made and whether it has been reviewed or updated; any relevant clinical developments or changes in the patient's personal circumstances since the decision was made; any more recent actions or decisions of the patient that indicate they may have changed their mind.

60. If there is doubt or disagreement about the validity or applicability of an advance refusal of treatment you should make further enquiries, where time permits, and seek a ruling from the court where necessary. In an emergency, where there is no time to investigate further, the presumption should be in favour of providing treatment, if it has a realistic chance of prolonging the patient's life.

61. If it is agreed, by you and those caring for the patient, that an advance refusal of treatment is invalid or not applicable, the reasons for reaching this view should be documented.

Recording and communicating decisions

62. You must make a record of the decisions made about a patient's treatment and care, and who was consulted in relation to those decisions.

63. You must do your best to ensure that all those consulted, and especially those responsible for delivering care, are informed of the decisions and are clear about the goals and the agreed care plan¹⁹.

64. You should check the hand-over arrangements to ensure that the agreed care plan is shared with professional and other carers involved in providing the patient's care. This is particularly important when patients move across different care settings (hospital, ambulance, care home) and during any out-of-hours period, as failure to

¹⁹ The Gold Standards Framework provides a tool to improve collaboration between care homes, GPs/Primary Care Teams, Specialist Palliative Care Teams and reduce the number of admissions to hospital in the last days of life. Available at www.goldstandardsframework.nhs.uk.

communicate this information can lead to inappropriate treatment being given as well as failure to meet patients' needs.

65. It is important that all involved are clear about their areas of responsibility and lines of accountability. You should ensure that you are clear about the scope and responsibilities of your role, and take steps to clarify any ambiguity or uncertainty about your own or others' responsibilities, with your employing or contracting body.

Reviewing decisions

66. A patient's condition may unexpectedly improve or may not progress as anticipated, or their views about the benefits and burdens of treatment may change over time. You should make sure that there are clear arrangements in place to review decisions²⁰. New decisions about starting or continuing with a treatment may be needed, in the light of changes in the patient's condition and circumstances, and it may be necessary to seek a second opinion.

Conscientious objections

67. If, because of your personal beliefs about providing life-prolonging treatment, you object to a patient's decision to refuse it or to a decision that such treatment will not be of overall benefit to a patient who lacks capacity to decide, you may withdraw from the patient's care. However, you must not do so without first ensuring that arrangements have been made for another doctor to take over your role. It is not acceptable to withdraw from a patient's care if this would leave the patient, or colleagues with nowhere to turn²¹.

Care after death

68. When a patient dies, your duty of care does not come to an end. For the patient's family and others close to them, their memories of the death, and of the

²⁰ For example, the Liverpool Care Pathway supports structured decision-making and review of patients' care. Available at www.lcp-mariecurie.org.uk and www.endoflifecareforadults.nhs.uk.

²¹ Refer to the GMC guidance 'Personal Beliefs and Medical Practice' (2008).

person who has died, may be affected by the way in which you behave at this very difficult time.

69. Death and bereavement affect different people in different ways, and an individual's response will also be influenced by factors such as their beliefs, culture, religion and values²². You must show respect for and respond sensitively to the wishes and needs of the bereaved, taking into account what you know of the patient's wishes about what should happen after their death, including the patient's views about sharing information²³.

70. You should ensure that the patient's body is treated with dignity and respect and, wherever possible, in line with any rituals for followers of their particular faith or beliefs. You must be professional and compassionate when confirming and pronouncing death and must follow the law, and statutory codes of practice, governing death certification. If there is any information on the death certificate that those close to the patient may not know about, or may not understand, you should explain this to them and answer their questions, taking account of the patient's wishes where known.

Organ donation

71. You should be prepared to explore with those close to the patient whether the patient had expressed any views about organ donation, and to discuss sensitively with them the possibility of donation.

72. You should follow any local procedures for identifying potential organ donors and, in appropriate cases, notifying the local transplant co-ordinator²⁴. You must take account of requirements in relevant legislation²⁵ and any supporting codes of

²² The Liverpool Care Pathway provides advice on meeting the spiritual and other personal needs of patients and their carers in the last days of life and into bereavement. www.endoflifecareforadults. Advice is also available from the Multi-faith group for healthcare chaplaincy www.mfghc.com; the Child Bereavement Trust www.childbereavement.org.uk; Cruse bereavement care, Scotland www.crusescotland.org.uk.

²³ Refer to GMC guidance *Confidentiality: protecting and providing information*, paragraph 30.

²⁴ *Donor Family Care Policy*. NHS UK Transplant (October 2004) www.organdonation.nhs.uk

²⁵ Human Tissue Act 2004. Human Tissue (Scotland) Act 2006.

practice²⁶ in any discussions that you might have with those close to the patient. You should make clear that any decision about whether the patient would be a suitable candidate for donation would be made by the transplant coordinator or team and not by you and the team providing treatment.

Audit of practice

73. There may be events arising from the care of particular patients within your team, unit or practice, which suggest ways of improving treatments or standards of end of life care. You should participate constructively in any local arrangements, such as clinical audit and case reviews, which aim to improve outcomes and identify and spread good practice.

Neonates, children and young people

74. Neonates, children and young people²⁷ are individuals with rights that must be respected. These are reflected in the decision-making framework set out in the GMC's guidance *0-18 years: guidance for all doctors*. It gives advice on:

- involving children and young people in decisions
- assessing capacity and best interests
- effective communication with children, their parents and other carers
- what to do when children or young people refuse treatment
- the different legal requirements across the UK for decision-making involving neonates, children and young people

²⁶ Human Tissue Authority Code of Practice 1: Consent (2006), and Code of Practice 2: donation of organs tissues and cells for transplantation (2006) www.hta.gov.uk.

The advice in this guidance on end of life treatment and care should be read in conjunction with *0-18 years: guidance for all doctors*.

75. The paragraphs below emphasise particular issues and principles, in both sets of guidance, to which you must pay special attention in reaching what may be very distressing end of life decisions.

76. As with other care, your primary duty is to the neonate, child or young person who is your patient, and any decisions you take must always be in their overall best interests.

77. Identifying the best interests of neonates, children or young people who have advanced life-limiting illnesses or are dying can be challenging. This is particularly so when there are uncertainties about the long-term outcomes of treatment, or in emergencies, and in the case of extremely premature neonates whose prospects for survival are known to be very poor. Complex and emotionally demanding decisions may have to be made, for example about whether to resuscitate and admit a baby to neonatal intensive care, and whether to continue invasive intensive care or replace it with palliative care. It can be very difficult to judge when the degree of suffering caused by treatment outweighs the benefits of the treatment to the baby.

78. You must take account of up to date, authoritative, clinical guidance²⁸ when considering such decisions, and consult a more experienced colleague when uncertainties remain about the range of options for managing the patient's condition or the likely outcomes for the patient. You should consider how best to support the

²⁷ A definition of 'children and young people' is in GMC guidance *0-18 years: guidance for all doctors*, at Appendix 1.

²⁸ *The Management of Babies born extremely preterm at less than 26 weeks of gestation. A framework for clinical practice at the time of birth*. Oct 2008. British Association of Perinatal Medicine www.bapm.org. *Withholding and withdrawing life-sustaining treatment in children. A framework for practice*. 2nd edition 2004. Royal College of Paediatrics and Child Health www.rcpch.ac.uk.

patient (so far as appropriate) and their parents or carers²⁹, to reach an understanding of the clinical issues.

79. You should listen to and respect children and young people's views about their health. You should involve them as much as possible in discussions about their care, whether or not they are able to make decisions for themselves. You should not withhold information about their diagnosis and prognosis that they are able to understand, unless they ask you to, or you judge that giving it might cause them serious harm³⁰.

80. Parents play an important role in assessing their child's best interests, and you should work in partnership with them when making decisions about the child's treatment. You should support parents, share with them the information they want or need about their child's condition and options for care, and take account of their views³¹. You should do your best to ensure that parents receive consistent messages from the different healthcare staff they are likely to come into contact with.

81. You should work constructively with the patient (where possible)³², their parents or carers and other members of the healthcare team, and strive to reach a consensus on treatment options and what course of action would be in the child or young person's overall best interests. Where disagreements arise, it is usually possible to resolve them, for example, by involving an independent advocate consulting more experienced colleagues, holding a case conference and/or ethics consultation, or using local mediation services.

82. If after taking such steps significant disagreement remains, you should seek legal advice on applying to the appropriate court for an independent ruling.

²⁹ Refer to *0-18 years; guidance for all doctors* for detailed advice on the different decision-making authority of people with parental responsibility, family members, and informal carers.

³⁰ In this context, 'serious harm' means more than that the patient might become upset, or decide to refuse treatment.

³¹ Parent support organisations such as BLISS (www.bliss.org.uk), Tiny Life www.tinylife.org.uk, Cerebra www.cerebra.org.uk publish helpful leaflets and give telephone support to parents and informal carers.

³² *Advocating for children*. January 2009. Royal College of Paediatrics and Child Health www.rcpch.ac.uk

Special challenges in applying the guidance

Clinically assisted nutrition and hydration

83. All patients are entitled to food and drink of adequate quantity and quality and to the help they need to eat and drink. Malnutrition and dehydration can be both a cause and consequence of ill health, so maintaining a healthy level of nutrition and hydration can help to prevent or treat illness and symptoms and improve treatment outcomes for patients. You should satisfy yourself that oral nutrition and hydration are being provided in a way that meets the patient's needs, and that any problems (such as difficulty swallowing or risk of choking) are being managed effectively.

84. Where patients are unable to take sufficient nutrition and/or hydration by mouth, even with support, you must carry out an assessment of their condition and their individual requirements for nutrition and/or hydration³³. You must consider what forms of clinically assisted nutrition or hydration may be required to meet their needs.

85. Clinically assisted nutrition and hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), nasogastric tube feeding or administration of fluid, 'PEG' or 'RIG' feeding tube through the abdominal wall. These are techniques that may prolong and improve the quality of a patient's life. However, they may also bring problems and complications of their own³⁴.

86. The current evidence about the benefits and burdens of these techniques in treating and managing patients towards the end of life is not clear cut³⁵. This can

³³ NICE guideline *Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition*. Feb 2006. www.nice.org.uk. [Artificial Nutrition and Hydration: guidance in end of life care for adults](#). National Council for Palliative Care (2007). The British Association for Parenteral and Enteral Nutrition provides advice on meeting the needs of patients at home and in different healthcare settings www.bapen.org.uk.

³⁴ An explanation of the different techniques and how they are used can be found in the NICE guideline *Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition*. Feb 2006.

³⁵ Refer to the discussion in *Improving Nutritional Care. A joint action plan from the Department of Health and Nutrition Summit stakeholders*. DH October 2007.

lead to clinical uncertainty and perhaps disagreement about the overall benefit in the circumstances of a particular patient. Assessments may be complicated by other factors, such as:

- a. Loss of interest in food and drink which can occur as patients' body systems begin to shut down
- b. Conditions such as stroke and Alzheimer's disease, which can impair a patient's thirst response
- c. Under-reporting of symptoms by patients.
- d. Loss of capacity to make decisions.
- e. Differing perceptions between the doctors, members of the healthcare team and the people who are close to a patient about the presence or severity of symptoms.

87. In the face of such uncertainties, concerns may arise about the possibility that a patient who is unconscious or semi-conscious, and whose wishes cannot be determined, might be experiencing distressing symptoms and complications or otherwise be suffering, because their needs for nutrition or hydration are not being met. Alternatively there may be concerns that attempts to meet a patient's perceived needs for nutrition or hydration may cause them avoidable suffering towards the end of their life. In some cases, patients and those close to them, or members of the healthcare team, may have strong beliefs that clinically assisted nutrition and hydration are not medical treatments but part of basic nurture for the patient and should always be provided.

88. In view of these concerns, it is essential that you base your decisions on up to date clinical evidence or other authoritative guidance. As the benefits and burdens are different for clinically assisted nutrition and hydration, you must assess these separately and seek a second opinion or expert advice if you are uncertain about them. In deciding which of the options for providing nutrition or hydration would be likely to meet a patient's assessed need, you must ensure that the patient, the health care team, and those close to the patient (where the patient lacks capacity to decide), are fully involved in the decision. You should take steps to help those

participating in the decision-making to understand your assessment of the patient's needs, and any uncertainties underlying the options you consider would meet those needs. You should reassure them that, whatever your decisions about providing clinically assisted nutrition or hydration, you will assess the patient for the presence of distressing symptoms, for example signs of pain, breathing difficulties, confusion, and dry mouth and provide relief.

Patients with capacity

89. If clinically assisted nutrition or hydration might prolong a patient's life, and that patient has capacity to make decisions about their care, you must offer these treatments to the patient. Following the framework in paragraph 17, you must explain to the patient the benefits, burdens, risks or complications associated with the treatments, so that they can make an informed decision about whether to accept the treatment.

Patients without capacity

90. If clinically assisted nutrition or hydration might prolong the life of a patient who lacks capacity to decide, you must be prepared to provide these treatments. Your discussions with the patient's representative and/or those close to the patient should be aimed at deciding whether these treatments would provide overall benefit to the patient. This decision must be based on a careful assessment of the patient's clinical condition and needs, and made in accordance with the framework in paragraph 18.

91. Where a patient's death is not imminent (expected within hours or days) but their condition is severe and the prognosis very poor, you may consider that clinically assisted nutrition or hydration, while likely to prolong their life, will cause them suffering which would be intolerable in all the circumstances. In such a case, as well as following the guidance in paragraph 18, you must seek a second or expert opinion from a senior clinician (who might be from another discipline) who has experience of the patient's condition but who is not already directly involved in the patient's care. You should also consider seeking legal advice. This will ensure that the patient's

interests have been thoroughly considered prior to the final decision about whether to stop, or not start, these treatments.

92. Where a patient is expected to die in a matter of hours or days, and you consider that clinically assisted nutrition or hydration will not prolong their life, it will not usually be appropriate to start treatment. However, you should assess the need for nutrition or hydration separately. For example, fluids may still provide symptom relief when nutrition is no longer of any overall benefit to the patient.

93. Where a patient's death is imminent and clinically assisted nutrition and hydration are already in use, but the burdens outweigh the possible benefits to the patient, it usually will be appropriate to stop the treatments. If a patient had previously requested that nutrition and hydration be continued until their death, you should take this into account in deciding what course of action would be in their overall interests, having regard to the harm that might be caused, on the one hand by going against the patient's wishes and on the other, by continuing to provide clinically assisted nutrition or hydration.

94. Where you are considering stopping nutrition and/or hydration for 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.

All patients

95. You must regularly review decisions about the provision of clinically assisted nutrition and hydration to take account of any changes in the patient's condition and follow the guidance in paragraph 22 on symptom management.

96. If you conclude that there is no need for clinically assisted nutrition or hydration (because the patient is able to take in sufficient food and water orally), or

that these treatments might hasten a patient's death (for example anorexia/cachexia syndromes in cancer patients) you are under no obligation to offer or provide them.

97. Where conflict arises about whether clinically assisted nutrition or hydration should be provided, either between you and other members of the healthcare team or between the team and the patient or those close to them, and this cannot be resolved by informal discussion or independent review, you should seek legal advice on applying to the appropriate court or statutory body for a ruling (see paragraph 42).

Cardiopulmonary resuscitation

98. CPR if attempted promptly can sometimes restart the heart and breathing of patients who have suffered a cardiac or respiratory arrest. However, CPR has a low success rate, particularly for patients with serious conditions who are in poor general health. CPR measures (which include chest compressions, clinically assisted respiration and defibrillation) also carry some risk of complications and harmful side effects and using them may prolong the dying process or suffering of a seriously ill patient in a manner which could be seen as degrading and undignified. Cardiac or respiratory arrest may be the terminal event in a patient's illness, for example if a patient is at the end-stage of an incurable disease, when attempts to resuscitate them will be futile and of no overall benefit to the patient.

99. Where patients with life-limiting conditions are admitted to hospital acutely unwell, or become clinically unstable in their home or other place of care, and are at foreseeable risk of cardiac or respiratory arrest, the question of whether CPR should be attempted in the event of an arrest should be considered as early as reasonably possible³⁶.

100. A decision about whether CPR should be attempted should be made only after careful consideration of all relevant factors and usually in discussion with the

³⁶ *Decisions relating to cardiopulmonary resuscitation*. Joint statement from the BMA, the Resuscitation Council (UK) and RCN (October 2007) www.resus.org.uk.

patient and those close to patients who lack capacity to decide. Relevant factors include:

- a. The likely clinical outcome, including the likelihood of successfully re-starting the patient's heart and breathing for a sustained period, the level of recovery that can realistically be expected after successful CPR and whether cardio-respiratory arrest is likely to recur³⁷.
- b. The patient's known or ascertainable wishes, including any information about previously expressed views, feelings, beliefs and values.
- c. The patient's human rights, including the right to life and the right to be free from degrading treatment.
- d. The likelihood of the patient experiencing severe unmanageable pain or other distressing side effects as a result of successful CPR.
- e. The level of awareness the patient has of their existence and surroundings.

101. Where patients lack capacity to make a decision about future CPR, the views of members of the healthcare team involved in the patient's care, including those who see the patient at home or in other healthcare settings, may be valuable in forming a view about the likely clinical effectiveness of attempting CPR and the likely overall benefits to the patient. You should make every effort to discuss a patient's CPR status with these healthcare professionals.

Discussions where CPR will not be successful

102. Where you judge that CPR should not be attempted because it will not be successful in restarting the heart and breathing, and the patient has not expressed a

³⁷ *Cardiopulmonary resuscitation - standards for clinical practice and training*. Joint statement from the Royal College of Anaesthetists, the Royal College of Physicians of London, the Intensive Care Society and the Resuscitation Council (UK). Available at www.resus.org.uk.

wish to discuss CPR, it is not always necessary or appropriate to initiate discussion with the patient .

103. You should take account of a patient's individual circumstances when considering whether to tell them about a Do Not Attempt Resuscitation (DNAR) decision. In most cases patients should be informed, but for some, for example those who know that they are approaching the end of their lives, information about interventions that would not be clinically successful will be unnecessarily burdensome and of little or no value. You must consider what is right for the patient and should not withhold information simply because conveying it is difficult or uncomfortable for you or the healthcare team.

104. If a patient who lacks capacity has appointed a welfare attorney whose authority extends to making decisions about clinical care, or if a court has appointed a deputy or guardian with similar authority to act on the individual's behalf, you should inform this person of a decision not to attempt CPR and the reason for it. If they request a second opinion you should arrange this, whenever possible.

Discussions where CPR may be successful

105. If CPR may be successful in re-starting a patient's heart and maintaining breathing for a sustained period, the benefits of prolonging life must be weighed against the potential burdens and risks to the patient. This is not solely a clinical decision and you must take account of the patient's broader interests which include their known or likely wishes and their views about whether the level of recovery and quality of life after successful CPR would be acceptable to them. You should discuss with the patient (or those close to a patient who lacks capacity to decide) whether CPR should be attempted in the circumstances that may surround a future cardio-respiratory arrest. You must provide them with accurate information about the burdens and risks of possible CPR measures³⁸ and the likely outcome for the patient of successful CPR.

³⁸ Refer to guidance published by the Resuscitation Council UK which gives details about immediate and advance resuscitation for adults, paediatric and newborn life support. A 'model patient information

106. You should explain, in a sensitive manner, any doubts that you and the healthcare team may have about whether the benefits of CPR would outweigh the burdens, or whether the level of recovery expected would be acceptable to the patient. You should offer the patient opportunities to talk about CPR (with support if they need it) and give them the information they want and need about the possible risks and adverse effects, so that they can make informed decisions about whether CPR should be attempted. However, you should not force information on the patient if they do not want it.

107. Any discussions with the patient (or those close to them) about whether to attempt CPR, and any decisions made, should be documented in the patient's record or advance care plan³⁹. If a DNAR decision is made and there has been no discussion with the patient because they have indicated a clear desire to avoid such discussion, you should note this in the patient's records.

108. Some patients may wish to receive CPR when there is only a small chance of restarting their heart or breathing and prolonging their life for more than a very short period, and in spite of the risk of distressing adverse effects. In such cases, you must provide the patient with accurate information about the nature of CPR measures⁴⁰ and the length of survival and quality of life that might realistically be expected if they were successfully resuscitated. You should aim to reach an agreed decision. However, if a patient with capacity still requests that no DNAR decision is made, you should respect their wishes. You should record that a decision about whether to attempt CPR must be made at the time of any future cardio-respiratory arrest, based on the available knowledge of the patient's condition prior to the event, and taking account of the importance that they attach to attempting CPR.

109. When discussing CPR with people close to a patient who lacks capacity and who do not have legal authority to make decisions on that patient's behalf, you

leaflet' is available from their website www.resus.org.uk. The NHS Lothian leaflet *Decisions about resuscitation: Information for patients, their relatives and carers*. (2007) is also available.

³⁹ Possible reference to 'locality registers' of patients receiving end of life care (England) and e-palliative care records (Scotland).

⁴⁰ The Liverpool Care Pathway provides an evidence base for the effectiveness of CPR in the last days of life. www.lcp-mariecurie.org.uk and at www.endoflifecareforadults.nhs.uk

should be clear that their role in the decision-making process is to advise the healthcare team about the patient's known or likely wishes, views and beliefs. You must not ask them to decide whether CPR should be attempted, or give them the impression that they are being asked to make such a decision.

Treatment and care after a CPR decision

110. The fact that a decision has been made to attempt CPR in the event of cardio-respiratory arrest does not mean that all other intensive treatments and procedures should also be used. For example, prolonged support for multi-organ failure in an intensive care unit (e.g. mechanical ventilation, renal dialysis or haemofiltration, circulatory support with drugs and/or an intra-aortic balloon pump) may be clinically inappropriate, if the patient is unlikely to survive this even though their heart has been re-started. When discussing the benefits and burdens of CPR with patients, it is important to ensure that this is understood through sensitive discussion with patients and those close to them.

111. A DNAR order applies only to CPR and does not imply that other treatments will be stopped or withheld. You must make clear to patients, people close to the patient and members of the healthcare team that all other treatment and care which provide overall benefit for the patient will be continued.

Emergencies and CPR

112. Emergencies can arise where there is no time to make a proper assessment of the patient's condition and the likely outcome of CPR. No previous decision about CPR may have been made and it may not be possible to ascertain the patient's views. In these circumstances, CPR should be attempted, unless you are certain you have sufficient information about the patient to judge that it will not be successful.

Legal Annex

This is not intended to be a comprehensive statement of the law or list of relevant legislation and case law, nor is it a substitute for up to date legal advice. It is for reference purposes only.

Consent and capacity

The GMC guidance *Consent: patients and doctors making decisions together* (2008) gives an overview of the statute and case law that affects all treatment decisions and the use of organs and tissue, and which relate to adults (with and without capacity to make their own decisions), neonates, children and young people www.gmc-uk.org/guidance/ethical_guidance/consent_guidance/index.asp

Special attention is drawn to the Mental Capacity Act 2005 (England & Wales) with its code of practice, and the Adults with Incapacity (Scotland) Act 2000 and its code of practice, which set out:

- Who has legal authority to make decisions on behalf of adults (people aged 16 and over) when they lack capacity to make their own decision.
- How adults can make provision for future decision-making by appointing attorneys; recording statements of their preferences; making advance decisions to refuse treatment.
- Statutory principles that must guide decisions made on behalf of an adult who lacks capacity.
- Requirements for supporting adults who have impaired capacity or lack capacity to make a particular decision, including the appointment of independent advocates.
- Factors to be considered in assessing a person's capacity to make a particular decision, including their ability to communicate.
- Factors to take into account in reaching a judgment about what course of action would be of overall benefit (in the person's best interests) where an adult lacks capacity to decide. This includes advice about

how to work with advance statements and advance refusals of treatment.

- Statutory safeguards to protect vulnerable adults in relation to, for example, serious medical treatments, research and possible deprivation of liberty.
- Processes for resolving disagreements (statutory requirements in Scotland) and for making referrals to the court, where necessary.

The MCA Code of Practice is a statutory code which doctors are expected to observe in their day-to-day treatment and care of adults who lack capacity to make a decision. Details of the Act and Code and access to training materials and guidance can be found on the websites of Department of Health (DH) England, Welsh Assembly and Office of the Public Guardian. Advice and support in working with the Act and Code in health and social care settings is currently available from Implementation Leads in NHS Trusts and Health Boards. Additional advice on appointing and working with Independent Mental Capacity Advocates (IMCAs) is available on the websites of DH England and the Welsh Assembly.

www.publicguardian.gov.uk/mca/mca.htm

www.dh.gov.uk/imca or email:IMCA@dh.gsi.gov.uk

<http://new.wales.gov.uk/topics/health/publications/health/guidance/imcaproviders/?lang=en>

The AWISA Code of Practice (Part 5: decisions about medical treatment and research) provides guidance on applying the Act which doctors are expected to take into account in their treatment and care of adults who lack capacity. Details of the Act and Code are available from the Scottish Government. Additional supporting guidance is published by the Mental Welfare Commission which also gives advice about working with the Act and Code.

www.scotland.gov.uk/Topics/Justice/law/awi

www.mwcscot.org.uk/newpublications/good_practice_guidance.asp

Human Rights Act 1998

The Human Rights Act 1998 came fully into force across the UK in 2000. The Act incorporates into domestic law the bulk of the rights set out in the European Convention on Human Rights (ECHR). The Act requires all 'public authorities', which includes the NHS, to act in accordance with the rights and duties set out in the Act. Doctors who provide services on behalf of the NHS are required to observe the Act, in reaching decisions about individual patients and in relation to other aspects of NHS service delivery.

The Convention rights that are most relevant to decisions about treatment and care towards the end of a patient's life are:

- a. Article 2 – the right to life and positive duty on public authorities to protect life.
- b. Article 3 - the right to be free from inhuman and degrading treatment.
- c. Article 5 – the right to security of the person.
- d. Article 8 – the right to respect for private and family life.
- e. Article 9 - the right to freedom of thought, conscience and religion.
- f. Article 14 - the right to be free from discrimination in the enjoyment of these other rights.

The Convention rights are open to a degree of interpretation, and since 2000 the Act has been used in a number of cases to challenge particular medical decisions. The case law to date confirms that the established ethical principles and obligations that underpin good medical practice are consistent with the rights and duties established under the ECHR¹. It is also clear that doctors' should continue to expect greater scrutiny of their decisions, bearing in mind that the Act allows the court to consider both the merits of a particular decision and the decision making process. So it is of

increased importance that decisions are made in a way that is transparent, fair and justifiable, and greater attention is paid to recording the detail of decisions and the reasons for them.

Case law

Doctors have a duty in law to protect the life and further the health of patients. A number of legal judgments on withholding and withdrawing treatment (mainly in English courts) have shown that the courts do not consider that protecting life always takes precedence over other considerations. The case law establishes a number of relevant principles. The summary below is our understanding of the key points. It is not intended as a definitive statement of the case law (the endnotes contain the case references):

- An act where the doctor's primary intentionⁱⁱ is to bring about a patient's death would be unlawfulⁱⁱⁱ.
- A competent adult patient may decide to refuse treatment even where refusal may result in harm to themselves or in their own death^{iv}. 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^v. 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^{vi}.
- Life prolonging treatment may lawfully be withheld or withdrawn from incompetent patients when commencing or continuing treatment is not in their best interests^{vii}.
- There is no obligation to give treatment that is futile and burdensome^{viii}.
- 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^{ix}.

- 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^x.
- The 'intolerability' of treatment is not the sole test of whether treatment is in a patient's best interests. The term 'best interests' encompasses medical, emotional and all other factors relevant to the patient's welfare^{xi}.
- A patient's best interests may be determined as meaning that a patient should not be subjected to more treatment than is necessary to allow him/her to die peacefully and with dignity^{xii}.
- All reasonable steps should be taken to overcome challenges in communicating with or managing the care of patients with disabilities, to ensure that they are provided with the treatment they need and which would be of overall benefit to the patient^{xiii}.
- Where clinicians and a child's family are in fundamental disagreement over the child's treatment, the views of the court should be sought^{xiv}.
- If a patient requests a treatment which their doctor has not offered and the doctor concludes that the treatment will not provide overall clinical benefit to the patient, the doctor is not obliged to provide it, although s/he should offer to arrange a second opinion^{xv}.
- Where artificial nutrition and hydration is necessary to keep a patient alive, the duty of care will normally require the doctor to provide it, if a competent patient wishes to receive it^{xvi}.
- Artificial nutrition and artificial hydration may be withheld or withdrawn where the patient does not wish to receive them; or where the patient is dying and the care goals change to palliation of symptoms and relief of suffering; or where the patient lacks capacity to decide and it is considered that providing artificial nutrition and hydration would not be in the patient's overall interests^{xvii}.
- 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^{xviii}. However, in practice, a court declaration should be obtained^{xix}.

- 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 to treatment or, in the case of an incompetent patient, any known views of the patient prior to becoming incapacitated and taking account of the views offered by those close to the patient^{xx}.
- When the Court is asked to reach a view about withholding or withdrawing 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 overall interests^{xxi}.

Endnotes

ⁱ 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.

ⁱⁱ R v Cox (1992) 12 BMLR 38.

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

^{iv} 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.

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

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

^{vii} Airedale NHS Trust v Bland [1993] 1 All ER 821.

^{viii} Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.

^{ix} Airedale NHS Trust v Bland [1993] 1 All ER 821 at page 860 per Lord Keith and page 866 per Lord Goff. Re T (Adult: Refusal of Treatment) [1992] 4 All ER 349 and Re AK (Medical Treatment: Consent) [2001] 1 FLR 129. W Healthcare NHS Trust v H [2005] 1 WLR 834

^x 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.

^{xi} Wyatt & Anor v Portsmouth Hospital NHS & Anor [2005] EWCA Civ 1181. Burke v GMC [2005] EWCA Civ 1003. An NHS Trust v MB [2006] EWHC 507 (Fam).

^{xii} NHS Trust v Ms D [2005] EWHC 2439 (Fam). Burke v GMC [2005] EWCA Civ 1003.

^{xiii} An NHS Trust v S & Ors [2003] EWHC 365 (Fam).

^{xiv} Glass v the United Kingdom (ECHR, 2004).

^{xv} Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614; Burke v GMC [2005] EWCA Civ 1003.

^{xvi} Burke v GMC [2005] EWCA Civ 1003.

^{xvii} Burke v GMC [2005] EWCA Civ 1003. NHS Trust v Ms D [2005] EWHC 2439 (Fam)

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

^{xix} 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.

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

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