

4 - End of Life Care: Consultation - Annex B

**End of Life Treatment and Care: Good Practice in Decision-Making**

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# 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. The purpose of this guidance is to help doctors to provide patients with high quality end of life care, including involvement of and support for their families and others who may have an interest in their welfare.
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* and *Consent: patients and doctors making decisions together*, to set out the approach that doctors should take to the particular challenges that arise in providing care towards the end of life.
3. 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 the care of their patients their first concern.
4. The 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 also help patients and the public understand what to expect of their doctors, in circumstances where patients and those close to them (family members, friends and carers) may be particularly vulnerable and in need of support.

## 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 is care that 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

The guidance applies to all patients, including extremely premature neonates.

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 but is particularly relevant in the last days of a patient's life, when the focus of treatment has generally moved from trying to cure disease and prevent deterioration to controlling 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<sup>1</sup> and mechanical ventilation. These treatments have many potential benefits including extending the lives of patients who might otherwise 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 GMC's guidance *Consent: Patients and Doctors Making Decisions Together* sets out the principles of good decision-making and provides advice about how to communicate effectively, and work towards achieving a consensus with patients (where they have capacity to decide), or those close to them, and within the healthcare team. This guidance expands on *Consent*

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<sup>1</sup> For the purposes of this guidance 'artificial' is defined as 'clinically assisted'

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

14. The problems that some patients (such as those with disabilities, who are elderly or from ethnic minorities) experience in accessing good quality care 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 familiar with its principles. Doctors providing NHS services must be able to demonstrate that their decisions are consistent with its terms. (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.) 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 there should always be a strong 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 always take account of the patient's views where these are known or can be ascertained.

### *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 who lack 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 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. Take account of the views of anyone who has legal authority to make the decision on their behalf<sup>2</sup>, or whom the patient has asked to be consulted, or who has been appointed to represent them.<sup>3</sup>
  - f. Work with those close to the patient and with 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 to be in the patient's best interests.<sup>4</sup>
  - 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 patients in England and Wales, a need to appoint an Independent Mental Capacity Advocate to represent the patient's interests.

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<sup>2</sup> Welfare attorneys and court-appointed guardians (Scotland), holders of lasting powers of attorney and court-appointed deputies (England).

<sup>3</sup> Independent Mental Capacity Advocates (IMCAs) in England and Wales

<sup>4</sup> [Insert definition of 'best interests']

19. *Consent: patients and doctors making decisions together* contains specific guidance on assessing a patient's capacity (paragraphs 71 - 74); supporting patients to participate in decision-making and helpful approaches to achieve clear, effective and sensitive communication with patients and those close to them (paragraphs 18 - 22).

## **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 live<sup>5</sup>, 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 patients' palliative care needs, and consider how to manage any pain, breathlessness, agitation or other distressing symptoms 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:

- e. up to date clinical evidence about efficacy, side effects and other risks
- f. relevant clinical guidelines on the treatment and management of the patient's condition, or of patients with similar underlying risk factors, such as

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<sup>5</sup> [Insert details of/links to clinical guidance]

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:
- g. you and the healthcare team have limited experience of a condition
  - h. you are in doubt about the range of options, or the benefits, burdens and risks of a particular option for the individual patient
  - i. 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 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 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) which provides 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 (*Consent* paragraphs 28-36).

### *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 or consultation with other clinicians. Uncertainty of this kind might arise, for example, in an emergency, an acute crisis in a patient's care, 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 for, 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 a positive act 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's family and carers where they are finding the decisions emotionally challenging.

*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 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 policy, 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.

34. You must

- j. Provide the best service possible within the resources available
- k. 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)
- l. 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.
- m. Be fair and non-discriminatory in decisions about prioritising patients
- n. 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*.

### *Assessing the overall benefit of treatment options*

36. Respect for human life will normally require you to take all reasonable steps to prolong a patient's life. However this requirement is not absolute. 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 which provide no overall benefit to the patient.

37. You must not continue with or start 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 inappropriate to provide potentially life-prolonging treatments where the patient is in the last stages of life and the care goals are changing 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, as set out in the framework at paragraph 17, and you should be careful to take account of the other factors relevant to the circumstances of each patient. In the case of a patient who lacks capacity, you should follow the law and related codes of practice which set out the factors to be considered in determining what would be of overall benefit for the patient. This may involve referral to the court in some cases.

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 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 supporting patients 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 the elderly and those with disabilities.

#### *Advance care planning*

42. 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 discussion and planning about how best to manage the patient's care.

43. End of life treatment and care is delivered by multi-disciplinary, multi-professional teams and across local health and social care services. To ensure timely access to safe, effective care and continuity in its delivery, it is important to plan ahead as much as possible to meet patients' individual needs.

44. 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, and to attend to any personal and other concerns that they would consider important towards the end of their life.

45. Where a patient has a condition that will impair their capacity as it progresses (such as dementia or motor neurone disease), 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:

- o. The patient's wishes, preferences or fears in relation to their future treatment and care
- p. The feelings, beliefs or values that may be influencing the patient's preferences and decisions
- q. The family members, friends, carers or representatives that the patient would like to be involved in decisions about their care
- r. 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
- s. The patient's preferred place of care (which may affect the treatment options available)
- t. The patient's needs for religious, spiritual or other personal support.

46. You must approach such discussions sensitively. 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.

47. Where a patient wants to nominate someone to make decisions on their behalf if they lose capacity, or if they want to refuse 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 directive<sup>6</sup>) and recommend that they get independent advice on how to do this<sup>7</sup>.

48. You should make a record of the discussion and of the decisions made. You should make sure that a record of the care plan is made available to the patient and others involved in their care, so that everyone is clear about what has been agreed. You should bear in mind that care plans need to be reviewed and updated as the situation or the patient's views change.

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<sup>6</sup> [Refer to Legal Annex. Add specific references from AWISA and MCA Codes of Practice]

<sup>7</sup> [Suggest sources of help e.g. Office of the Public Guardian]

49. Paragraphs 13 – 17 of *Consent: patients and doctors making decisions together* explains what to do 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.

#### Advance requests for treatment

50. 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 statement requesting 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.

51. 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 53-54 of this guidance. As these concerns often arise in relation to CPR and clinically assisted nutrition and hydration, you should refer to paragraphs 82-110 which provide specific advice on how to respond to requests for these treatments.

#### Advance refusals of treatment

52. Some patients worry about over-treatment towards the end of their life and they may want to make an advance decision or directive<sup>8</sup> 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 55 - 60.

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<sup>8</sup> [Explain terminology in E&W and Scotland]

## How to act on advance requests for treatment

53. 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.

54. 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).

## How to act on advance decisions to refuse treatment

55. A valid advance decision or directive refusing treatment (an '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 mind.

56. 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 to consider vary between the four UK countries, reflecting differences in the legal framework (see Legal Annex for details of legislation). However, the main considerations are that:

- u. 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)
- v. The patient had capacity to make the decision at the time it was made (UK wide)
- w. The patient was not subject to undue influence in making the decision (UK wide)
- x. 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 only)
- y. The decision has not been withdrawn by the patient (UK wide)
- z. The patient has not, since the decision was made, appointed an attorney to make such decisions on their behalf (England, Wales and Scotland)
- aa. The decision is clearly applicable to the circumstances that have arisen (UK wide).
- bb. Since the decision was made, the patient has not done anything which is clearly inconsistent with its terms (UK wide).

57. 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.

58. 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.

59. If there is doubt or disagreement about the validity and 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.

60. 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*

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

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

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

64. 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*

65. 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. You should make sure that there are clear arrangements in place to review decisions

and if necessary to make new ones in the light of changes in the patient's condition and circumstances.

### *Conscientious objections*

66. 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. You must not leave patients, or colleagues, with nowhere to turn.

### *Care after death*

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

68. 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, values. 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.

69. 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

70. 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 with them the possibility of donation.

71. You should follow any local procedures for identifying potential organ donors and, in appropriate cases, notifying the local transplant co-ordinator. You must take account of the codes of practice issued by the Human Tissue Authority 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*

72. You must participate in clinical audit of your decisions to help improve knowledge of the outcomes of treatment and non-treatment decisions in end of life care. There may also be events arising from the care of particular patients which raise issues within a unit or team, and you should encourage and participate constructively in discussions to resolve those issues.

## **Special challenges in applying the guidance**

### *Neonates, children and young people*

73. The framework for decision-making in end of life care for neonates, children and young people<sup>9</sup> is essentially the same as for any other phase of clinical care.

74. Neonates, children and young people are individuals with rights that must be respected. The general principles which you should follow when caring for, and making decisions about neonates, children and young people are set out in the GMC's guidance *0-18 years: guidance for all doctors*. It gives advice on:

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<sup>9</sup> See Appendix 1 of *0-18 years: guidance for all doctors* for a definition of children and young people.

- 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

*0-18 years: guidance for all doctors* should be read in conjunction with the rest of this guidance on end of life treatment and care. The paragraphs below emphasise particular issues and principles to which special attention must be paid in reaching what may be very distressing end of life decisions.

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

76. 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.

77. You must take account of up to date, authoritative, clinical guidance<sup>10</sup> 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

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

78. 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 believe that giving it might cause them serious harm<sup>11</sup>.

79. 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 views. 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.

80. You should work constructively with the patient (where possible), their parents 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.

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

#### *Clinically assisted nutrition and hydration*

82. 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

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<sup>10</sup> [Insert guidance RCPCH and BAPM links]

<sup>11</sup> In this context, 'serious harm' means more than that the patient might become upset, or decide to refuse treatment.

outcomes for patients. You should satisfy yourself that oral nutrition and hydration is 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.

83. 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 hydration. You must consider what forms of clinically assisted nutrition or hydration may be required to meet their needs.

84. 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<sup>12</sup>. 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 own.

85. The current evidence about the benefits and burdens of these techniques in treating and managing patients towards the end of life is not clear cut<sup>13</sup>. This can 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.

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<sup>12</sup> [Insert links to/details of information about these techniques]

<sup>13</sup> [Insert links to/details of up-to-date information]

86. 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.

87. 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 (where able to decide), 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

88. 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. In accordance with 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

89. If clinically assisted nutrition or hydration might prolong the life of a patient who lacks capacity, 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.

90. 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.

91. 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.

92. Where a patient's death is imminent and clinically assisted nutrition or 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.

93. 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

94. You must regularly review decisions about provision of clinically assisted nutrition and hydration to take account of any changes in the patient's condition (paragraph 65) and follow the guidance in paragraph 22 on symptom management.

95. 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.

96. 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. 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.

#### *Cardiopulmonary resuscitation*

97. Cardiopulmonary resuscitation (CPR)<sup>14</sup> 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 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

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<sup>14</sup> CPR measures include external chest compression, clinically assisted respiration and defibrillation.

degrading and undignified.<sup>15</sup> 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 are likely to be futile and of no overall benefit to the patient.

98. 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 should be considered as early as reasonably possible.

99. A decision about whether CPR should be attempted should be made only after careful consideration of all relevant factors and in discussion with the patient, or 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 recur.
- 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.
- e. The level of awareness the patient has of their existence and surroundings.

100. Where patients lack capacity to make a decision about 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

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<sup>15</sup> Add references to clinical guidelines

benefits to the patient. You should make every effort to discuss a patient's CPR status with these healthcare professionals.

#### Discussions where CPR is unlikely to be successful

101. Where you consider that CPR should not be attempted because it is unlikely to be successful, and the patient has not expressed a wish to discuss CPR, it is not always necessary or appropriate to initiate discussion with the patient to explore their wishes regarding CPR.

102. 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.

103. 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

104. 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. Discussion with the patient (or those close to a patient who lacks capacity to decide) about whether CPR

should be attempted is an essential part of the decision-making process in these circumstances.

105. When a patient with capacity is at foreseeable risk of cardio-respiratory arrest, and you and healthcare team have doubts 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 explain this to the patient, in a sensitive manner. You should offer them opportunities to talk about CPR and give them the information they want and need about the possible risks and adverse effects, so that they can make informed decisions about it. But you should not force information on them if they do not want it.

106. Any discussions with the patient about whether to attempt CPR, and any decisions made, should be documented in the patient's record. 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.

107. Some patients may wish to receive CPR even if there is only a small chance of restarting their heart or breathing, or of 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 measures procedures and the length of survival and quality of life that might realistically be expected if they were successfully resuscitated. Where a patient with capacity then requests that no DNAR decision is made in light of that discussion, you should respect the patient's wishes.

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

109. 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. artificial ventilation, renal dialysis or haemofiltration, and 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.

110. 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.

## Legal Annex

### *Consent and capacity*

*Consent: Patients and Doctors Making Decisions Together* includes an overview of the statute and case law that affects treatment decisions and the use of organs and tissue.

### *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 ECHR. 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*

Below is an indicative list of key cases which are relevant to decisions about end of life treatment and care.

This is not intended as a substitute for up to date legal advice, especially as the law differs between England and Wales, Scotland and Northern Ireland. It is for reference purposes only.

- i. R v Cox (1992) 12 BMLR 38.
- ii. Airedale NHS Trust v Bland [1993] 1 All ER 821
- iii. Re JT (Adult: Refusal of Medical Treatment) [1998] 1 FLR 48
- iv. 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. Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.
- viii. Re T (Adult: Refusal of Treatment) [1992] 4 All ER 349.
- ix. Re B [1981] 1 WLR 421;
- x. Re C (A Minor) [1989] All ER 782;

- xi. Re R (Adult: Medical Treatment) [1996] 2 FLR 99.
- xii. Law Hospital NHS Trust v Lord Advocate 1996 SLT 848.
- xiii. Practice Note (Official Solicitor: Declaratory Proceedings: Medical and Welfare Decisions for Adults Who Lack Capacity) [2001] 2 FLR.
- xiv. Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614;
- xv. Re G (Persistent Vegetative State) [1995] 2 FCR 46.
- xvi. A National Health Trust v D (2000) 55 BMLR 19;
- xvii. NHS Trust A v M and NHS Trust B v H (2000) 58 BMLR 87.
- xviii. Re: A (Children) (Conjoined twins: surgical separation) [2000] 4 All ER 961.
- xix. Ms B v An NHS Hospital Trust [2002] EWHC 429 (Fam)
- xx. An NHS Trust v S & Ors [2003] EWHC 365 (Fam)
- xxi. W Healthcare NHS Trust v H [2005] 1 WLR 834
- xxii. NHS Trust v. Ms D (2005) EWHC 2439 (Fam)
- xxiii. Wyatt & Anor v Portsmouth Hospital NHS & Anor [2005] EWCA Civ 1181 (12 October 2005)
- xxiv. Burke v GMC [2005] EWCA Civ 1003
- xxv. An NHS Trust v MB [2006] EWHC 507 (Fam)