



Treatment and care towards the end of life:

good practice in decision making

General
Medical
Council

Regulating doctors
Ensuring good medical practice

The duties of a doctor registered with the General Medical Council

Patients must be able to trust doctors with their lives and health. To justify that trust you must show respect for human life and you must:

- Make the care of your patient your first concern
- Protect and promote the health of patients and the public
- Provide a good standard of practice and care
 - Keep your professional knowledge and skills up to date
 - Recognise and work within the limits of your competence
 - Work with colleagues in the ways that best serve patients' interests
- Treat patients as individuals and respect their dignity
 - Treat patients politely and considerately
 - Respect patients' right to confidentiality
- Work in partnership with patients
 - Listen to patients and respond to their concerns and preferences
 - Give patients the information they want or need in a way they can understand
 - Respect patients' right to reach decisions with you about their treatment and care
 - Support patients in caring for themselves to improve and maintain their health
- Be honest and open and act with integrity
 - Act without delay if you have good reason to believe that you or a colleague may be putting patients at risk
 - Never discriminate unfairly against patients or colleagues
 - Never abuse your patients' trust in you or the public's trust in the profession.

You are personally accountable for your professional practice and must always be prepared to justify your decisions and actions.

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Medical
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About this guidance

The General Medical Council (GMC) is the statutory regulator for the medical profession in the UK, and this guidance applies to doctors working in all four UK countries.

This guidance is based on long-established ethical principles, which include doctors' obligations to show respect for human life; to protect the health of patients; to treat patients with respect and dignity; and to make the care of their patients their first concern. It expands on the principles of good practice in the GMC's *Good Medical Practice* (2006) and *Consent: patients and doctors making decisions together* (2008), and replaces the booklet *Withholding and Withdrawing Life-Prolonging Treatments* (2002).

This guidance takes account of, and is consistent with, current law across the UK, including the laws on decision making for patients who lack capacity (the *Adults with Incapacity (Scotland) Act 2000* and the *Mental Capacity Act 2005*); the law prohibiting killing (including euthanasia) and assisting suicide; and the requirements of the *Human Rights Act 1998*. However, it is not intended as a statement of the legal principles or a substitute for legal advice. Doctors must seek up-to-date advice when there is uncertainty about how a particular decision might be viewed in law, in the jurisdiction in which they practise.

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

This guidance can be read on our website, where the online version contains links to the documents referenced in the text, footnotes, references, endnotes and legal annex. All GMC guidance documents can be read on our website: www.gmc-uk.org

How this guidance applies to you

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.

The footnotes, references, endnotes and legal annex are intended only to provide information that may be helpful additional background. References to publications by other organisations are intended only as examples of available national resources.

This 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.

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.

Guidance

- 1** Patients who are approaching the end of their life need high-quality treatment and care that support them to live as well as possible until they die, and to die with dignity. This guidance identifies a number of challenges in ensuring that patients receive such care, and provides a framework to support you in addressing the issues in a way that meets the needs of individual patients. Providing treatment and care towards the end of life will often involve decisions that are clinically complex and emotionally distressing; and some decisions may involve ethical dilemmas and uncertainties about the law that further complicate the decision-making process. This guidance is intended to help you, in whatever context you are working, to address these issues effectively with patients, the healthcare team and those who have an interest in the patient's welfare. It seeks to ensure that people who are close to the patient (partners, family, carers and others) are involved and supported, while the patient is receiving care and after the patient has died.

- 2** For the purposes of this guidance, patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

 - (a)** advanced, progressive, incurable conditions
 - (b)** general frailty and co-existing conditions that mean they are expected to die within 12 months
 - (c)** existing conditions if they are at risk of dying from a sudden acute crisis in their condition
 - (d)** life-threatening acute conditions caused by sudden catastrophic events.

This guidance also applies to those extremely premature neonates whose prospects for survival are known to be very poor, and to patients who are diagnosed as being in a persistent vegetative state¹ (PVS), for whom a decision to withdraw treatment may lead to their death.

- 3** The most challenging decisions in this area are generally about withdrawing or not starting a treatment when it has the potential to prolong the patient's life. This may involve treatments such as antibiotics for life-threatening infection, cardiopulmonary resuscitation (CPR), renal dialysis, 'artificial' nutrition and hydration (for the purpose of this guidance 'artificial' is replaced by 'clinically assisted'²) and mechanical ventilation. The evidence of the benefits, burdens and risks of these treatments is not always clear cut, and there may be uncertainty about the clinical effect of a treatment on an individual patient, or about the particular benefits, burdens and risks for that patient. In some circumstances these treatments may only prolong the dying process or cause the patient unnecessary distress. Given the uncertainties, you and others involved in the decision-making process may need reassurance about what is ethically and legally permissible, especially when deciding whether to withdraw a potentially life-prolonging treatment.
- 4** In addition it is now widely agreed that high-quality treatment and care towards the end of life includes palliative care that focuses on managing pain and other distressing symptoms; providing psychological, social and

1 Persistent vegetative state is also referred to as 'permanent vegetative state'.

2 'Artificial nutrition and hydration' is the phrase sometimes used in healthcare settings. However, we believe that 'clinically assisted nutrition and hydration' is a more accurate description of the use of a drip, a nasogastric tube or a tube surgically implanted into the stomach, to provide nutrition and fluids.

spiritual support to patients; and supporting those close to the patient. However, it is not always recognised that palliative care can be provided at any stage in the progression of a patient's illness, not only in the last few days of their life.

- 5 The framework for decision making in care towards the end of life is essentially the same as for any other phase of clinical care. The principles of good decision making for all stages of care are set out in *Consent: patients and doctors making decisions together*. When an issue in this guidance is covered in more detail in *Consent*, this is indicated in the text.

- 6 It is important to note that we use the term 'overall benefit' to describe the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide. GMC guidance on overall benefit, applied with the decision-making principles in paragraphs 7-13, is consistent with the legal requirement to consider whether treatment 'benefits'³ a patient (Scotland), or is in the patient's 'best interests'⁴ (England, Wales and Northern Ireland), and to apply the other principles set out in the *Mental Capacity Act 2005* and *Adults with Incapacity (Scotland) Act 2000*.

3 'Benefit' as set out in the *Adults with Incapacity (Scotland) Act 2000*.

4 'Best interests' as set out in the *Mental Capacity Act 2005* (in England and Wales) and common law in Northern Ireland.

Principles

Equalities and human rights

- 7** You must give patients who are approaching the end of their life the same quality of care as all other patients. You must treat patients and those close to them with dignity, respect and compassion, especially when they are facing difficult situations and decisions about care. You must respect their privacy and right to confidentiality.

- 8** Some groups of patients can experience inequalities in getting access to healthcare services and in the standard of care provided. It is known that some older people, people with disabilities and people from ethnic minorities have received poor standards of care towards the end of life. This can be because of physical, communication and other barriers, and mistaken beliefs or lack of knowledge among those providing services, about the patient's needs and interests. Equalities, capacity and human rights laws reinforce your ethical duty to treat patients fairly.

- 9** If you are involved in decisions about treatment and care towards the end of life, you must be aware of the *Human Rights Act 1998* and its main provisions, as your decisions are likely to engage the basic rights and principles set out in the Act⁵.

⁵ 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.

Presumption in favour of prolonging life

- 10** Following established ethical and legal (including human rights) principles, decisions concerning potentially 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. This presumption will normally require you to take all reasonable steps to prolong a patient's life. However, there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views, if they are known or can be found out.

Presumption of capacity

- 11** You must work on the presumption that every adult patient has the capacity to make decisions about their care and treatment. You must not assume that a patient lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), beliefs, apparent inability to communicate or because they make a decision that others disagree with or consider unwise.

Maximising capacity to make decisions

- 12** If a patient's capacity to make a decision may be impaired, you must provide the patient with all appropriate help and support to maximise their ability to understand, retain, use or weigh up the information needed to make that decision or communicate their wishes. You must assess their capacity to make each decision, at the time it needs to be made. You can find detailed guidance about maximising and assessing a patient's capacity in *Consent: patients and doctors making decisions together* and in the codes of practice supporting the *Mental Capacity Act 2005* and *Adults with Incapacity (Scotland) Act 2000*⁶.

Overall benefit

- 13** If an adult patient lacks capacity to decide, the decisions you or others make on the patient's behalf must be based on whether treatment would be of overall benefit to the patient (see paragraphs 40-46 for more about assessing overall benefit), and which option (including the option not to treat) would be least restrictive of the patient's future choices. When you are responsible for making the decision about overall benefit, you must consult with those close to the patient who lacks capacity, to help you reach a view (see paragraphs 15-16).

⁶ Information about this legislation, the supporting codes of practice and related guidance can be found in the legal annex.

Decision-making models

Patients who have capacity to decide⁷

- 14** If a patient has capacity to make a decision for themselves, this is the decision-making model that applies:
- (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 judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks 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, burdens and risks 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. 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 clinically appropriate for them, the doctor should discuss the issues with the patient and explore the reasons for their request. If, after

⁷ Additional considerations apply to children and young people who have capacity to decide – see the section on neonates, children and young people at paragraphs 90–108.

discussion, the doctor still considers that the treatment would not be clinically appropriate to the patient, they do not have to provide the treatment. They should explain their reasons to the patient and explain any other options that are available, including the option to seek a second opinion or access legal representation.

Adults who lack capacity to decide⁸

15 If you assess that a patient lacks capacity to make a decision, you must:

- (a)** be clear what decisions about treatment and care have to be made
- (b)** check the patient's medical record for any information suggesting that they have made a potentially legally binding advance decision or directive refusing treatment
- (c)** make enquiries as to whether someone else holds legal authority to decide which option would provide overall benefit for the patient (an attorney or other 'legal proxy'⁹). You should bear in mind that the powers held by a legal proxy may not cover all healthcare decisions, so you should check the scope of their decision-making authority¹⁰
- (d)** take responsibility for deciding which treatment will provide overall benefit to the patient, when no legal proxy exists, and you are the

⁸ Advice on children who lack capacity is in the section on neonates, children and young people.

⁹ Legal proxies include: a person holding a Lasting Power of Attorney (England and Wales) or Welfare Power of Attorney (Scotland), a court-appointed deputy (England and Wales) or a court-appointed guardian or intervener (Scotland). Northern Ireland currently has no provision for appointing legal proxies with power to make healthcare decisions.

¹⁰ Powers of attorney must be registered with the Offices of the Public Guardian in England and Wales and Scotland. Information is available on their websites. The role of the various legal proxies is explained in the codes of practice that support the relevant capacity laws – see the legal annex.

doctor with responsibility for the patient's care.¹¹ You must consult those close to the patient and members of the healthcare team to help you make your decisions.

- 16** Taking account of the considerations in paragraph 15, this is the decision-making model that applies if a patient lacks capacity:
- (a) The doctor, with the patient (if they are able to contribute) and the patient's carer¹², makes an assessment of the patient's condition taking into account the patient's medical history and the patient and carer's knowledge and experience of the condition.
 - (b) The doctor uses specialist knowledge, experience and clinical judgement, together with any evidence about the patient's views (including advance statements, decisions or directives), to identify which investigations or treatments are clinically appropriate and are likely to result in overall benefit for the patient.
 - (c) If the patient has made an advance decision or directive refusing a particular treatment, the doctor must make a judgement about its validity and its applicability to the current circumstances. If the doctor concludes that the decision or directive is legally binding, it must be followed in relation to that treatment. Otherwise it should be taken into account as information about the patient's previous wishes. (See paragraphs 67-74 on assessing the legal status of advance decisions and directives.)

¹¹ In these circumstances you will have legal authority to make decisions about treatment, under the *Adults with Incapacity (Scotland) Act 2000* (subject to issuing a certificate of incapacity), or the *Mental Capacity Act 2005* (England and Wales), or the common law in Northern Ireland. See the legal annex.

¹² The 'carer' for these purposes means the person supporting the patient and representing their interests in the consultation about their health and what might be needed in terms of any investigations, treatment or care.

- (d) If an attorney or other legal proxy has been appointed to make healthcare decisions for the patient, the doctor explains the options to the legal proxy (as they would do for a patient with capacity), setting out the benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe would provide overall benefit for the patient. The legal proxy weighs up these considerations and any non-clinical issues that are relevant to the patient's treatment and care, and, considering which option would be least restrictive of the patient's future choices, makes the decision about which option will be of overall benefit. The doctor should offer support to the legal proxy in making the decision, but must not pressurise them to accept a particular recommendation.
- (e) As well as advising the legal proxy, the doctor must involve members of the healthcare team and those close to the patient¹³ as far as it is practical and appropriate to do so¹⁴, as they may be able to contribute information about the patient that helps the proxy to reach a decision. If the legal proxy does not have the power to make a particular decision, the doctor must take account of the proxy's views (as someone close to the patient) in the process of reaching a decision.
- (f) In circumstances in which there is no legal proxy with authority to make a particular decision for the patient, and the doctor is responsible for making the decision, the doctor must consult with members of the healthcare team and those close to the patient (as far as it is practical

13 The term 'those close to the patient' means anyone nominated by the patient, close relatives (including parents if the patient is a child), partners and close friends, paid or unpaid carers outside the healthcare team and independent advocates. It may include attorneys for property and financial affairs and other legal proxies, in some circumstances.

14 Who it is appropriate and practical to consult will depend on, for example, a patient's previous request; what reasonable steps can be taken to consult within the time available before a decision must be made; and any duty to consult or prioritise specific people set out in relevant capacity laws or codes.

and appropriate to do so) before reaching a decision. When consulting, the doctor will explain the issues; seek information about the patient's circumstances; and seek views about the patient's wishes, preferences, feelings, beliefs and values. The doctor may also explore which options those consulted might see as providing overall benefit for the patient, but must not give them the impression they are being asked to make the decision. The doctor must take the views of those consulted into account in considering which option would be least restrictive of the patient's future choices and in making the final decision about which option is of overall benefit to the patient.

- (g) In England and Wales, if there is no legal proxy, close relative or other person who is willing or able¹⁵ to support or represent the patient and the decision involves serious medical treatment¹⁶, the doctor must approach their employing or contracting organisation about appointing an Independent Mental Capacity Advocate (IMCA), as required by the *Mental Capacity Act 2005* (MCA). The IMCA will have authority to make enquiries about the patient and contribute to the decision by representing the patient's interests, but cannot make a decision on behalf of the patient.
- (h) If a disagreement arises about what would be of overall benefit, the doctor must attempt to resolve the issues following the approach set out in paragraphs 47-48.
- (i) If a legal proxy or other person involved in the decision making asks for a treatment to be provided which the doctor considers would not be clinically appropriate and of overall benefit to the patient, the doctor should explain the basis for this view and explore the reasons for the

15 No one 'willing or able' generally means where there is no one close to the patient to consult or those available are unable or feel unable to participate in the decision making. The MCA Code of Practice gives more information.

16 Serious medical treatment is defined in the MCA Code of Practice, where the role of the IMCA is also set out.

request. If after discussion the doctor still considers that the treatment would not be clinically appropriate and of overall benefit, they are not obliged to provide it. However, as well as explaining the reasons for their decision, the doctor should explain to the person asking for the treatment the options available to them. These include the option of seeking a second opinion, applying to the appropriate statutory body for a review (Scotland), and applying to the appropriate court for an independent ruling.

Working with the principles and decision-making models

Role of relatives, partners and others close to the patient

- 17** The people close to a patient can play a significant role in ensuring that the patient receives high-quality care as they near the end of life, in both community and hospital settings. Many parents, other close relatives and partners, as well as paid and unpaid carers, will be involved in discussing issues with a patient, enabling them to make choices, supporting them to communicate their wishes, or participating directly in their treatment and care. In some cases, they may have been granted legal power by the patient, or the court, to make healthcare decisions when the patient lacks capacity to make their own choices.
- 18** It is important that you and other members of the healthcare team acknowledge the role and responsibilities of people close to the patient. You should make sure, as far as possible, that their needs for support are met and their feelings respected, although the focus of care must remain on the patient.
- 19** Those close to a patient may want or need information about the patient's diagnosis and about the likely progression of the condition or disease, in order to help them provide care and recognise and respond to changes in the patient's condition. If a patient has capacity to make decisions, you should check that they agree to you sharing this information. If a patient lacks capacity to make a decision about sharing information, it is reasonable to assume that, unless they indicate otherwise, they would want those closest to them to be kept informed of relevant information about their

general condition and prognosis. (There is more guidance in our booklet on *Confidentiality*.) You should check whether a patient has nominated someone close to them to be kept informed and consulted about their treatment.

- 20** When providing information, you must do your best to explain clinical issues in a way the person can understand, and approach difficult or potentially distressing issues about the patient's prognosis and care with tact and sensitivity. (See paragraphs 33-36 on addressing emotional difficulties and possible sources of support.)
- 21** When discussing the issues with people who do not have legal authority to make decisions on behalf of a patient who lacks capacity, you should make it clear that their role is to advise the healthcare team about the patient's known or likely wishes, views and beliefs. You must not give them the impression they are being asked to make the decision.

Working in teams and across service boundaries

- 22** Most treatment and care at the end of life is delivered by multi-disciplinary and multi-agency teams, working together to meet the needs of patients as they move between different health and social care settings and access different services. This can include GP practices, local care homes, pharmacies, hospices, ambulance services, local hospitals, and local authority and voluntary sector support services. You must communicate effectively with other members of the health and social care team or teams

involved in a patient's care, sharing with them the information necessary to provide the patient with safe, effective and timely care. (See paragraphs 75-77 on recording and communicating decisions.) When considering options for treatment and care, and reviewing the patient's progress, you should consult other members of the team who may have information about the patient or relevant knowledge and experience that may help in managing or treating the patient's condition.

- 23** You must make sure that you understand the scope and responsibilities of your own role in the healthcare team, the roles and specialist skills of other health and social care team members, and the lines of accountability for the patient's care.¹⁷ You should take steps to clarify any ambiguity about your own or others' responsibilities with your employing or contracting organisation if you have concerns that the ambiguity may compromise patient safety.¹⁸

Making sound clinical judgements

- 24** The starting point for reaching good decisions is careful consideration of the patient's clinical situation, whether providing care in a community or a hospital setting. You must carry out a thorough assessment of the patient's condition and consider the likely prognosis. It can be difficult to estimate when a patient is approaching the end of life, and you should allow for a range of possibilities when planning care.ⁱ

¹⁷ See *Good Medical Practice* (2006), paragraphs 41-42 at http://www.gmc-uk.org/guidance/good_medical_practice/working_with_colleagues.asp

¹⁸ GMC guidance on *Raising Concerns about Patient Safety* (2006) provides more detailed advice http://www.gmc-uk.org/guidance/ethical_guidance/raising_concerns.asp. www.goldstandardsframework.nhs.uk

- 25** 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).
- 26** You must also give early consideration to the patient's palliative care needs, and take steps to manage any pain, breathlessness, agitation or other distressing physical or psychological symptomsⁱⁱ that they may be experiencing, as well as keeping their nutrition and hydration status under review.
- 27** You must seek advice¹⁹ or a second opinion²⁰ from a colleague with relevant experience (who may be from another specialty, such as palliative care, or another discipline, such as nursing) if:
- (a) you and the healthcare team have limited experience of the condition
 - (b) you are uncertain about how to manage a patient's symptoms effectively
 - (c) you are in doubt about the range of options, or the benefits, burdens and risks of a particular option for the individual patient

19 Advice should usually be from an experienced colleague outside the team. Advice may be obtained by telephone, if necessary, provided you have given that colleague up-to-date information about the patient's condition.

20 A second opinion should be from a senior clinician with experience of the patient's condition but who is not directly involved in the patient's care. It should be based on an examination of the patient by the clinician.

- (d) there is a serious difference of opinion between you and the patient, within the healthcare team, or between the team and those close to a patient who lacks capacity, about the preferred option for a patient's treatment and care
- (e) it is decided that clinically assisted nutrition or hydration should be withdrawn or not started in the circumstances set out in paragraphs 119-120.

Explaining the clinical issues

- 28** You should explore treatment options with patients (and with those close to them if appropriate) focusing on the goals of care, and explaining 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 diagnosis or the benefits, burdens and risks of a treatment option. This is particularly the case for treatments such as cardio-pulmonary resuscitation (CPR) and clinically assisted nutrition and hydration, as the public's knowledge about the clinical complexities may be limited.
- 29** Patients and those close to them may also draw incorrect 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.
- 30** You should be open about any underlying uncertainties, as this helps to build trust and reduce the scope for later conflict. You can find detailed advice on how to communicate clearly and effectively with patients and

those close to them, especially when explaining the side effects or other risks associated with treatments, in *Consent: patients and doctors making decisions together* (paragraphs 7-12, 18-25 and 28-36).

Addressing uncertainty

- 31** If there is a reasonable degree of uncertainty about whether a particular treatment will provide overall benefit for a patient who lacks capacity to make the decision, the treatment should be started in order to allow a clearer assessment to be made.

- 32** You must explain clearly to those close to the patient and the healthcare team that the treatment will be monitored and reviewed, and may be withdrawn at a later stage if it proves ineffective or too burdensome for the patient in relation to the benefits. You should explain the basis on which the decision will be made about whether the treatment will continue or be withdrawn.

Emotional difficulties in end of life decision making

- 33** Some members of the healthcare team, or people who are close to the patient, may find it more difficult to contemplate withdrawing a life-prolonging treatment than to decide not to start the treatment in the first place. This may be because of the emotional distress that can accompany a decision to withdraw life-prolonging treatment, or because they would feel responsible for the patient's death. However, you should not allow these anxieties to override your clinical judgement and lead you either not to start treatment that may be of some benefit to the patient, or to continue treatment that is of no overall benefit.

- 34** 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 withdraw, or not to start a treatment will be reviewed in the light of changes in the clinical situation.
- 35** You should offer advice about any support that may be available for the patient, for those close to them and for members of the healthcare team, if they are finding the situation emotionally challenging. Sources of support include patient and carer support and advocacy services, counselling and chaplaincy services, and ethics support networks.ⁱⁱⁱ
- 36** You should do your best to make sure that patients who may feel pressured by family or carers to accept or refuse particular investigations or treatments are given the time, information and help they need to reach their own decisions.

Resource constraints

- 37** Decisions about what treatment options can be offered may be complicated by resource constraints – such as funding restrictions on certain treatments in the NHS, or lack of availability of intensive care beds. In such circumstances, you must provide as good a standard of care as you can for the patient, while balancing sometimes competing duties towards the wider population, funding bodies and employers.²¹ There will often be no simple solution. Ideally, decisions about access to treatments should be

²¹ See *Good Medical Practice* (2006), paragraph 9.

made on the basis of an agreed local or national policy^{iv} that 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 consider properly the patient's legal rights (see paragraphs 7-9).

- 38** If 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 that set out agreed criteria for access to the particular treatment (such as national service frameworks and NICE and SIGN guidelines)
 - (c) make sure that decisions about prioritising patients are fair and based on clinical need and the patient's capacity to benefit, and not simply on grounds of age, race, social status or other factors that may introduce discriminatory access to care
 - (d) be open and honest with the patient (if they have capacity), or those close to them, and the rest of the healthcare team about the decision-making process and the criteria for prioritising patients in individual cases.
- 39** You should not withdraw or decide not to start treatment if doing so would involve significant risk for the patient and the only justification is resource constraints. 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 guidance on *Raising concerns about patient safety* (2006).

Assessing the overall benefit of treatment options

Weighing the benefits, burdens and risks

- 40** The benefits of a treatment that may prolong life, improve a patient's condition or manage their symptoms must be weighed against the burdens and risks for that patient, before you can reach a view about its overall benefit. For example, it may be of no overall benefit to provide potentially life-prolonging but burdensome treatment in the last days of a patient's life when the focus of care is changing from active treatment to managing the patient's symptoms and keeping them comfortable.
- 41** The benefits, burdens and risks 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.
- 42** Patients who have capacity will reach their own view about what personal factors they wish to consider and the weight they wish to attach to these alongside the clinical considerations. (See the model for decision making in paragraph 14.)
- 43** In the case of patients who lack capacity, their legal proxy will make these judgements with advice from you and others involved in the patient's care. If you are responsible for making the decision about overall benefit, those close to the patient and members of the healthcare team are likely to have knowledge about the patient's wishes, values and preferences and any other personal factors that should be taken into account. (See the model for decision making in paragraph 16.) You may also find information about the patient's wishes in their notes, advance care plan or other record, such as an advance request for or refusal of treatment.

Avoiding bias

- 44** Some patients, and those close to them, may not be aware of the range of services and treatments available to them, which could have a bearing on the options they would see as offering overall benefit. You should satisfy yourself that the patient has sufficient information and support so that they are not disadvantaged in accessing beneficial treatment and care.
- 45** It may be particularly difficult to arrive at a view about the overall benefit of a treatment if the patient has problems in communicating their wishes and preferences, or lacks capacity. In such cases you must not simply rely on your own values or on those of the people consulted about the patient. You should take all reasonable steps to maximise the patient's ability to participate in the decision-making process. You can find detailed advice about how to approach this in *Consent: patients and doctors making decisions together*.
- 46** You must be careful not to rely on your personal views about a patient's quality of life and to avoid making judgements based on poorly informed or unfounded assumptions about the healthcare needs of particular groups, such as older people and those with disabilities.^v

Resolving disagreements

- 47** You should aim to reach a consensus about what treatment and care would be of overall benefit to a patient who lacks capacity. Disagreements may arise between you and those close to the patient, or between you and members of the healthcare team, or between the healthcare team and those close to the patient. Depending on the seriousness of any disagreement, it is usually possible to resolve it; for example, by involving an independent advocate, seeking advice from a more experienced colleague, obtaining a second opinion, holding a case conference, or using local mediation services. In working towards a consensus, you should take into account the different decision-making roles and authority of those you consult, and the legal framework for resolving disagreements.
- 48** If, having taken these steps, there is still significant disagreement, you should seek legal advice on applying to the appropriate statutory body for review (Scotland) or appropriate court for an independent ruling.²² The patient, those authorised to act for them and those close to them should be informed, as early as possible, of any decision to start such proceedings, so that they have the opportunity to participate or be represented.

²² The courts will consider whether treatment is in the patient's 'best interests' (England, Wales and Northern Ireland). The courts in Scotland, and the Mental Welfare Commission for Scotland's Nominated Practitioner, will consider whether treatment is of 'benefit' to the patient. See the legal annex.

- 49** In situations in which a patient with capacity to decide requests a treatment and does not accept your view that the treatment would not be clinically appropriate, the steps suggested above for resolving disagreement may also be helpful.

Advance care planning

The benefits

- 50** As treatment and care towards the end of life are delivered by multi-disciplinary teams often working across local health, social care and voluntary sector services, you must plan ahead as much as possible to ensure timely access to safe, effective care and continuity in its delivery to meet the patient's needs.^{vi}
- 51** The emotional distress and other pressures inherent in situations in which patients are approaching the end of their life sometimes lead to misunderstandings and conflict between doctors and patients and those close to them, or between members of the healthcare team. However, this can usually be avoided through early, sensitive discussion and planning about how best to manage the patient's care.

What to discuss

- 52** Patients whose death from their current condition is a foreseeable possibility are likely to want the opportunity (whether they are in a community or hospital setting) to decide what arrangements should be made to manage the final stages of their illness. This could include having access to palliative care, and attending to any personal and other matters that they consider important towards the end of their life.^{vii}

- 53** If a patient in your care has a condition that will impair their capacity as it progresses, 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, others close to the patient or any legal proxies that the patient would like to be involved in decisions about their care
 - (d) interventions which may be considered or undertaken in an emergency, such as cardiopulmonary resuscitation (CPR), when it may be helpful to make decisions in advance
 - (e) the patient's preferred place of care (and how this may affect the treatment options available)
 - (f) the patient's needs for religious, spiritual or other personal support.
- 54** Depending on the patient's circumstances, it may also be appropriate to create opportunities for them to talk about what they want to happen after they die. Some patients will want to discuss their wishes in relation to the handling of their body, and their beliefs or values about organ or tissue donation.

- 55** You must approach all such discussions sensitively. If you are unsure how best to do this or how to respond to any non-clinical issues raised by the patient, you should refer to relevant guidelines on good practice in advance care planning.^{viii} If the patient agrees, you should involve in the discussions other members of the healthcare team, people who are close to the patient, or an independent advocate.

When patients do not want to know

- 56** Some patients may not be ready to think about their future care, or may find the prospect of doing so too distressing. However, no-one else can make a decision on behalf of an adult who has capacity. If a patient asks you to make decisions on their behalf or wants to leave decisions to a relative, partner or friend, you should explain that it is important that they understand the options open to them, and what the treatment will involve. If they do not want this information, you should try to find out why.
- 57** If the patient still does not want to know in detail about their condition or the treatment, you should respect their wishes as far as possible. But you must explain the importance of providing at least the basic information they need in order to give valid consent to a proposed investigation or treatment. This is likely to include what the investigation or treatment aims to achieve and what it will involve. For example, whether a procedure is invasive; what level of pain or discomfort they might experience and what can be done to minimise it; what they should do to prepare for the investigation or treatment; and whether it involves any serious risks.

- 58** If the patient insists that they do not want even this basic information, you must explain the potential consequences of carrying out an investigation or treatment if their consent may be open to subsequent legal challenge. You must record the fact that the patient has declined relevant information and who they asked to make the decision about treatment. You must also make it clear that they can change their mind and have more information at any time.

When others want information to be withheld from the patient

- 59** Apart from circumstances in which a patient refuses information, you should not withhold information necessary for making decisions (including when asked by someone close to the patient), unless you believe that giving it would cause the patient serious harm. In this context 'serious harm' means more than that the patient might become upset or decide to refuse treatment. If you withhold information from the patient, you must record your reasons for doing so in the medical records, and be prepared to explain and justify your decision. You should regularly review your decision and consider whether you could give information to the patient later, without causing them serious harm.

Formalising a patient's wishes

- 60** If 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 directive.²³ You should support a patient who has

²³ The *Mental Capacity Act 2005* (MCA) and the *Adults Within Incapacity (Scotland) Act 2000* legislation make provision for adults to grant powers of attorney to make healthcare decisions. Northern Ireland proposes similar legislation. The MCA sets out statutory requirements for making advance refusals of life-prolonging treatments. See the legal annex.

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.^{ix}

Recording and sharing the advance care plan

- 61** You must 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 is shared with others involved in their care (provided that the patient agrees), so that everyone is clear about what has been agreed. (See also paragraphs 22-23 about working in teams and across service boundaries.) If a patient makes an advance refusal of treatment, you should encourage them to share this information with those close to them, with other doctors, and with key health and social care staff involved in their care.
- 62** You must bear in mind that advance care plans need to be reviewed and updated as the patient's situation or views change.

Acting on advance requests for treatment

- 63** When planning ahead, some patients worry that they will be unreasonably denied certain treatments towards the end of their life, and so they may wish to make an advance request for those treatments. Some patients approaching the end of life want to retain as much control as possible over the treatments they receive and may want a treatment that has some prospects of prolonging their life, even if it has significant burdens and risks.

- 64** When responding to a request for future treatment, you should explore the reasons for the request and the degree of importance the patient attaches to the treatment. You should explain how decisions about the overall benefit of the treatment would be influenced by the patient's current wishes if they lose capacity (see the model in paragraph 16). You should make clear that, although future decisions cannot be bound by their request for a particular treatment, their request will be given weight by those making the decision.
- 65** If a patient has lost capacity to decide, you must provide any treatment you assess to be of overall benefit to the patient. When assessing overall benefit, you should take into account the patient's previous request, what you know about their other wishes and preferences, and the goals of care at that stage (for example, whether the focus has changed to palliative care), and you should consult the patient's legal proxy or those close to the patient, as set out in the decision-making model in paragraph 16. The patient's previous request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.
- 66** If significant disagreement arises between you and the patient's legal proxy, those close to the patient, or members of the healthcare team, about what would be of overall benefit, you must take steps to resolve the disagreement (see paragraphs 47-48).

Acting on advance refusals of treatment

- 67** Some patients worry that towards the end of their life they may be given medical treatments that they do not want. So they may want to make their

wishes clear about particular treatments in circumstances that might arise in the course of their future care. When discussing any proposed advance refusal, you should explain to the patient how such refusals would be taken into account if they go on to lose capacity to make decisions about their care.

When advance refusals are binding

68 If a patient lacks capacity and information about a written or verbal advance refusal of treatment is recorded in their notes or is otherwise brought to your attention, you must bear in mind that valid and applicable advance refusals must be respected. A valid advance refusal that is clearly applicable to the patient's present circumstances will be legally binding in England and Wales²⁴ (unless it relates to life-prolonging treatment, in which case further legal criteria must be met). Valid and applicable advance refusals are potentially binding in Scotland²⁵ and Northern Ireland²⁶, although this has not yet been tested in the courts.

Non-binding advance refusals

69 Written and verbal advance refusals of treatment that are not legally binding, should be taken into account as evidence of the person's wishes when you are assessing whether a particular treatment would be of overall benefit to them.

²⁴ The code of practice supporting the *Mental Capacity Act 2005*, which uses the legal term 'advance decision', sets out detailed criteria that determine when advance decisions about life-prolonging treatments are legally binding – see the legal annex.

²⁵ The code of practice supporting the *Adults with Incapacity (Scotland) Act 2000*, which uses the legal term 'advance directive', gives advice on their legal status and how advance directives should be taken into account in decisions about treatment.

²⁶ In Northern Ireland there is no statutory provision or case law covering advance refusals, but it is likely that the principles established in English case law precedents would be followed.

Assessing the validity of advance refusals

70 If you are the clinician with lead responsibility for the patient's care, you should assess both the validity and the applicability of any advance refusal of treatment that is recorded in the notes or that has otherwise been brought to your attention. The factors you should consider are different in the four UK countries, reflecting differences in the legal framework (see the legal annex). However, in relation to validity, 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 old or over 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) the patient made the decision on the basis of adequate information about the implications of their choice (UK wide)
- (e) if 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 only²⁷)
- (f) the decision has not been withdrawn by the patient (UK wide)
- (g) the patient has not appointed an attorney, since the decision was made, to make such decisions on their behalf (England, Wales and Scotland)
- (h) more recent actions or decisions of the patient are clearly inconsistent with the terms of their earlier decision, or in some way indicate they may have changed their mind.

²⁷ These requirements are set out in the MCA and its Code of Practice, Chapter 9.

Assessing the applicability of advance refusals

- 71** In relation to judgements about applicability, the following considerations apply across the UK:
- (a) whether the decision is clearly applicable to the patient's current circumstances, clinical situation and the particular treatment or treatments about which a decision is needed
 - (b) whether the decision specifies particular circumstances in which the refusal of treatment should not apply
 - (c) how long ago the decision was made and whether it has been reviewed or updated (this may also be a factor in assessing validity)
 - (d) whether there are reasonable grounds for believing that circumstances exist which the patient did not anticipate and which would have affected their decision if anticipated, for example any relevant clinical developments or changes in the patient's personal circumstances since the decision was made.

Doubt or disagreement about the status of advance refusals

- 72** 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 believe otherwise.
- 73** If there is doubt or disagreement about the validity or applicability of an advance refusal of treatment, you should make further enquiries (if time permits) and seek a ruling from the court if necessary. In an emergency, if there is no time to investigate further, the presumption should be in favour of providing treatment, if it has a realistic chance of prolonging life, improving the patient's condition, or managing their symptoms.

- 74** 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

- 75** 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.
- 76** You must do your best to make sure that all those consulted, especially those responsible for delivering care, are informed of the decisions and are clear about the goals and the agreed care plan, unless the patient indicates that particular individuals should not be informed.
- 77** You should check the handover arrangements where you work, and use the available systems and arrangements for information storage and exchange, to ensure that the agreed care plan is shared within the healthcare team, with both paid and unpaid carers outside the team and with other health professionals involved in providing the patient's care.^{x, xi} This is particularly important when patients move across different care settings (hospital, ambulance, care home) and during any out-of-hours period. Failure to communicate some or all relevant information can lead to inappropriate treatment being given (for example, DNACPR decisions not being known about) and failure to meet the patient's needs (for example, their wish to remain at home not being taken into account).

Reviewing decisions

- 78** A patient's condition may improve unexpectedly, or may not progress as anticipated, or their views about the benefits, burdens and risks of treatment may change over time. You should make sure that there are clear arrangements in place to review decisions.^{xii} 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 or, if this is not possible, advice from an experienced colleague.

Conscientious objections

- 79** You can withdraw from providing care if your religious, moral or other personal beliefs about providing life-prolonging treatment lead you to object to complying with:
- (a) a patient's decision to refuse such treatment, or
 - (b) a decision that providing such treatment is not of overall benefit to a patient who lacks capacity to decide.

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 turn. Refer to our guidance on *Personal Beliefs and Medical Practice* (2008) for more information.

- 80** If you disagree with a decision to withdraw or not to start a life-prolonging treatment on the basis of your clinical judgement about whether the treatment should be provided, you should follow the guidance in paragraphs 47-48 about resolving disagreements.

Organ donation

- 81** If a patient is close to death and their views cannot be determined, you should be prepared to explore with those close to them whether they had expressed any views about organ or tissue donation, if donation is likely to be a possibility.^{xiii}
- 82** You should follow any national procedures for identifying potential organ donors and, in appropriate cases, for notifying the local transplant coordinator.^{xiv} You must take account of the requirements in relevant legislation^{xv} and in any supporting codes of practice^{xvi}, in any discussions that you have with the patient or those close to them. 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.

Care after death

- 83** Your professional responsibility does not come to an end when a patient dies. 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.

The wishes and needs of the bereaved

84 Death and bereavement affect different people in different ways, and an individual's response will be influenced by factors such as their beliefs, culture, religion and values.^{xvii} 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 their views about sharing information.²⁸ You should be prepared to offer support and assistance to the bereaved, for example, by explaining where they can get information about, and help with, the administrative practicalities following a death; or by involving other members of the team, such as nursing, chaplaincy or bereavement care staff.^{xviii}

Certification, post-mortems, and referral to a coroner or procurator fiscal

85 You must be professional and compassionate when confirming and pronouncing death and must follow the law, and statutory codes of practice, governing completion of death and cremation certificates.^{xix} If it is your responsibility to sign a death or cremation certificate, you should do so without unnecessary delay. If there is any information on the death certificate that those close to the patient may not know about, may not understand or may find distressing, you should explain it to them sensitively and answer their questions^{xx}, taking account of the patient's wishes if they are known.

²⁸ Disclosure of information after a patient's death is covered at paragraphs 70-72 of the GMC guidance on *Confidentiality*.

- 86** You must comply with the legal requirements where you work for reporting deaths to a coroner (England, Wales and Northern Ireland) or procurator fiscal (Scotland). You should be prepared to answer questions from those close to the patient about reporting procedures and post-mortems, or to suggest other sources of information and advice.^{xxi}
- 87** You must treat the patient's body with dignity and respect. You should make sure, wherever possible, that the body is handled in line with their personal religious or other beliefs.

Training and audit

- 88** You should be familiar with relevant guidelines and developments that affect your work in providing care towards the end of life, and regularly take part in educational activities that maintain and develop your competence and performance in this area. You must keep up to date with the law and any supporting codes of practice that are relevant to this area and apply where you work.
- 89** There may be events arising from the care of a particular patient by your team, unit or practice that suggest ways of improving treatments or standards of care for patients approaching the end of life. You should participate constructively in any local arrangements, such as clinical audit and case reviews, that aim to improve outcomes and identify and spread good practice.

Neonates, children and young people

- 90** Children, including neonates, and young people are individuals with rights that must be respected. This means that, if they are able to express a view and take part in decision making, you must listen to them and take account of what they have to say about things that affect them, respecting their decisions and confidentiality. You have a duty to safeguard and protect the health and well-being of children and young people. You must also consider the role and responsibilities of parents and others close to them, but your primary duty is to the child or young person who is your patient.
- 91** Our guidance, *0-18 years: guidance for all doctors*, provides detailed advice on applying these principles when caring for children and young people. The advice below focuses on helping you to apply the principles in situations in which children or young people may be approaching the end of their life.

Considering the benefits, burdens and risks of treatment

- 92** Decisions about treatment for children and young people must always be in their best interests.²⁹ This means weighing the benefits, burdens and risks of treatment for the individual child. A child's best interests are not always limited to clinical considerations and, as the treating doctor, you should be careful to take account of any other factors relevant to the circumstances of each child.
- 93** Identifying the best interests of children or young people who may be approaching the end of life can be challenging. This is particularly the case when there are uncertainties about the long-term outcomes of treatment,

²⁹ 'Best interests' is used here as the term is widely accepted and used across the UK in relation to decisions involving children and young people. It involves weighing the benefits, burdens and risks of treatment, as do decisions about 'overall benefit' in the case of adults who lack capacity to decide.

when emergencies arise, and in the case of extremely premature neonates whose prospects for survival are known to be very poor.^{xxii} Complex and emotionally demanding decisions may have to be made; for example, about whether to resuscitate and admit a neonate to intensive care, and whether to continue invasive intensive care or replace it with palliative care. It can be very difficult to judge when the burdens and risks, including the degree of suffering caused by treatment, outweigh the benefits of the treatment to the patient.

- 94** You must take account of up-to-date, authoritative clinical guidance^{xxiii} when considering what treatment might be in a child or young person's best interests. If there are uncertainties about the range of options for managing their condition, or the likely outcomes, you should seek advice or a second opinion as early as possible from a colleague with relevant expertise (who may be from another specialty, such as palliative care, or another discipline, such as nursing).
- 95.** Parents³⁰ play an important role in assessing their child's best interests, and you should work in partnership with them when considering decisions about their child's treatment. You should support parents, and must share with them the information they want or need, in a way that they can understand, about their child's condition and options for care (subject to considerations of confidentiality). You must take account of their views when identifying options that are clinically appropriate and likely to be in the child's best interests.^{xxiv}

30 'Parent' means anyone holding 'parental authority'. For details of who can hold parental authority refer to *0-18 years: guidance for all doctors* http://www.gmc-uk.org/guidance/ethical_guidance/children_guidance_index.asp

- 96** You must be able to explain and justify the factors that you judge should be taken into account when considering decisions about what treatment might be in the best interests of a child or young person. You must not rely on your personal values when making best interests decisions. You must be careful not to make judgements based on poorly informed or unfounded assumptions about the impact of a disability on a child or young person's quality of life.

Making the decision

- 97** You can provide medical treatment to a child or young person with their consent if they have capacity to make the decision, or with the consent of a parent or the court. Detailed guidance on the different decision-making authority of people with parental responsibility, family members and informal carers is provided in the GMC's *0-18 years: guidance for all doctors*.
- 98** You can provide emergency treatment without consent to save the life of, or prevent serious deterioration in the health of, a child or young person.

Children and young people who have capacity

- 99** You must decide whether the child or young person is able to understand the nature, purpose and possible consequences of investigations or treatments you propose, as well as the consequences of not having treatment. Only if they are able to understand, retain, use and weigh this information, and communicate their decision to others, can they consent to an investigation or treatment.

- 100** The capacity to consent depends more on young people's ability to understand and weigh up options than on age. When assessing a young person's capacity to consent, you should bear in mind that:
- (a) at 16 a young person can be presumed to have capacity to consent
 - (b) a young person under 16 may have the capacity to consent, depending on their maturity and ability to understand.
- 101** It is important that you assess maturity and understanding on an individual basis, and with regard to the complexity and importance of the decision to be made. You should remember that a young person who has the capacity to consent to straightforward, relatively risk-free treatment may not necessarily have the capacity to consent to complex treatment involving high risks or serious consequences. The capacity to consent can also be affected by their physical and emotional development and by changes in their health and treatment.
- 102** You should listen to and respect children and young people's views about their health and consider how best to support them to reach an understanding of the clinical issues, so far as they are able. 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 if you judge that giving it might cause them serious harm. In this context 'serious harm' means more than that the child might become upset or decide to refuse treatment.

- 103** You should work constructively with the child or young person if possible, and with their parents or carers and other members of the healthcare team, and strive to reach a consensus on treatment options and on what course of action would be in their best interests. You should be aware of the arrangements for advocacy^{xxv} and mediation where you work so that you can advise the child and their parents where to get help and support in making their decision if they want or need it.

Children and young people who lack capacity

- 104** If a child lacks capacity to consent, you should discuss with their parents the treatments you assess to be clinically appropriate, and seek their consent to the treatment they judge to be in the child's best interests. It is usually sufficient to have consent from one parent, but if more than one person holds parental authority you should encourage them to reach a consensus. If after discussion, you and the parents reach a consensus that life-prolonging treatment would not be in the child's best interests and the treatment is withdrawn or not started, you must make sure that any distressing symptoms are addressed and the child is kept as comfortable as possible. You must monitor the child's condition and be prepared to reassess the benefits, burdens and risks of treatment in light of changes in their condition. You must keep the parents fully involved.

- 105** If a young person aged 16 or 17 lacks capacity, in Scotland you can make decisions on the same basis as for an adult who lacks capacity to decide (see paragraphs 15-16). In England, Wales and Northern Ireland, you should follow the guidance at paragraph 104, but if a parent is not available you can make the decision about treatment and care following the guidance at paragraph 16(f).

Neonates and infants

- 106** It may be particularly difficult to make a decision on the basis of what is in the best interests of a neonate or infant. If, when considering the benefits, burdens and risks of treatment (including resuscitation and clinically assisted nutrition and hydration) you conclude that, although providing treatment would be likely to prolong life, it would cause pain, suffering and other burdens that would outweigh any benefits and you reach a consensus with the child's parents and healthcare team that it would be in the child's best interests to withdraw, or not start the treatment, you may do so. However, in the case of decisions about clinically assisted nutrition and hydration, before you reach a definite decision to withdraw or not to start treatment, you must seek a second opinion (or, if this is not possible, advice) following the guidance at paragraph 121. Whatever decision is made, you must make sure that any distressing symptoms that the child may be experiencing are managed effectively and that the child's condition is reviewed regularly.

Parents' concerns and anxieties

- 107** You should be sensitive to the concerns and anxieties that parents may have when decisions have to be made about withdrawing or not starting potentially life-prolonging treatment. For example, parents may feel responsible for any adverse outcomes and want reassurance that all appropriate treatment for their child is being offered. You must listen to their concerns, consider carefully their views about changes in their child's condition, and make sure they have access to information or support if they need or want it. You should try to make sure that they receive consistent, clear messages about their child's care or condition from different members of the healthcare team.

Resolving disagreements

- 108** If disagreements arise about what course of action would be in a child or young person's best interests, it is usually possible to resolve them by, for example, involving an independent advocate; seeking advice from a more experienced colleague; obtaining an independent second opinion; by holding a case conference or ethics consultation; or by using local mediation services. If, after taking such steps, significant disagreement remains, you should seek legal advice on applying to the appropriate court for an independent ruling. Approaching the court should be seen as a constructive way of thoroughly exploring the issues and providing reassurance for the child and parents that the child's interests have been properly considered in the decision.

Meeting patients' nutrition and hydration needs

- 109** 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 must keep the nutrition and hydration status of your patients under review. You should be satisfied that nutrition and hydration are being provided in a way that meets your patients' needs, and that if necessary patients are being given adequate help to enable them to eat and drink.
- 110** If a patient refuses food or drink³¹, or has problems eating or drinking, you should first assess and address any underlying physical or psychological causes that could be improved with treatment or care. For example, some patients stop eating because of depression, or pain caused by mouth ulcers or dentures, or for other reasons that can be addressed. If a patient needs assistance in eating or drinking that is not being provided, or if underlying problems are not being effectively managed, you should take steps to rectify the situation, if you can. If you cannot, you should inform an appropriate person within the organisation that is responsible for the patient's care.

31 The offer of food and drink by mouth is part of basic care (as is the offer of washing and pain relief) and must always be offered to patients who are able to swallow without serious risk of choking or aspirating food or drink. Food and drink can be refused by patients at the time it is offered, but an advance refusal of food and drink has no force.

- 111** If you are concerned that a patient is not receiving adequate nutrition or hydration by mouth, even with support, you must carry out an assessment of their condition and their individual requirements. You must assess their needs for nutrition and hydration separately and consider what forms of clinically assisted nutrition or hydration may be required to meet their needs.^{xxvi}

Clinically assisted nutrition and hydration

- 112** Clinically assisted nutrition includes intravenous feeding, and feeding by nasogastric tube and by percutaneous endoscopic gastrostomy (PEG) and radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. All these means of providing nutrition also provide fluids necessary to keep patients hydrated. Clinically assisted hydration can also be provided by intravenous or subcutaneous infusion of fluids through a 'drip'. The terms 'clinically assisted nutrition' and 'clinically assisted hydration' do not refer to help given to patients to eat or drink, for example by spoon feeding.
- 113** Providing nutrition and hydration by tube or drip may provide symptom relief, or prolong or improve the quality of the patient's life; but they may also present problems.^{xxvii} The current evidence about the benefits, burdens and risks of these techniques as patients approach the end of life is not clear-cut.^{xxviii} This can lead to concerns that patients who are unconscious or semi-conscious may be experiencing distressing symptoms and complications, or otherwise be suffering either because their needs for nutrition or hydration are not being met or because attempts to meet their perceived needs for nutrition or hydration may be causing them avoidable suffering.
- 114** Nutrition and hydration provided by tube or drip are regarded in law as medical treatment³², and should be treated in the same way as other medical interventions. Nonetheless, some people see nutrition and hydration, whether taken orally or by tube or drip, as part of basic nurture

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

for the patient that should almost always be provided. For this reason it is especially important that you listen to and consider the views of the patient and of those close to them (including their cultural and religious views) and explain the issues to be considered, including the benefits, burdens and risks of providing clinically assisted nutrition and hydration. You should make sure that patients, those close to them and the healthcare team understand that, when clinically assisted nutrition or hydration would be of overall benefit, it will always be offered; and that if a decision is taken not to provide clinically assisted nutrition or hydration, the patient will continue to receive high-quality care, with any symptoms addressed.

- 115** If disagreement arises between you and the patient (or those close to a patient who lacks capacity), or you and other members of the healthcare team, or between the team and those close to the patient, about whether clinically assisted nutrition or hydration should be provided, you should seek resolution following the guidance in paragraphs 47-49. You should make sure that the patient, or someone acting on their behalf, is informed and given advice on the patient's rights and how to access their own legal advice or representation.

Patients who have capacity³³

- 116** If you consider that a patient is not receiving adequate nutrition or hydration by mouth, you should follow the decision model in paragraph 14. You must assess the patient's nutrition and hydration needs separately and

33 Additional considerations apply to decisions about clinically assisted nutrition and hydration involving children and young people with capacity (see paragraphs 90-103).

offer the patient those treatments you consider to be clinically appropriate because, for example, they would provide symptom relief or would be likely to prolong the patient's life. You must explain to the patient the benefits, burdens and risks associated with the treatments, so that the patient can make a decision about whether to accept them.

- 117** If you assess that clinically assisted nutrition or hydration would not be clinically appropriate, you must monitor the patient's condition and reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration as the patient's condition changes. If a patient asks you to provide nutrition or hydration by tube or drip, you should discuss the issues with the patient and explore the reasons for their request. You must reassess the benefits and burdens of providing the treatment requested, giving weight to the patient's wishes and values. When the benefits, burdens and risks are finely balanced, the patient's request will usually be the deciding factor. However, if after discussion you still consider that the treatment would not be clinically appropriate, you do not have to provide it. But you should explain your reasons to the patient and explain any other options that are available, including the option to seek a second opinion.

Adult patients who lack capacity³⁴

- 118** If a patient lacks capacity and cannot eat or drink enough to meet their nutrition or hydration needs, you must assess whether providing clinically assisted nutrition or hydration would be of overall benefit to them, following the decision model in paragraph 16 and guidance in paragraphs 40-48. Clinically assisted nutrition or hydration will usually be of overall

³⁴ General advice on children who lack capacity is in the section on neonates, children and young people. Decisions about clinically assisted nutrition and hydration involving neonates and infants are discussed at paragraph 106.

benefit, if for example they prolong life or provide symptom relief. You must assess the patient's nutrition and hydration needs separately. You must monitor the patient's condition, and reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration as the patient's condition changes.

Adult patients who lack capacity and are not expected to die within hours or days

- 119** If a patient is in the end stage of a disease or condition, but you judge that their death is not expected within hours or days, you must provide clinically assisted nutrition or hydration if it would be of overall benefit to them, taking into account the patient's beliefs and values, any previous request for nutrition or hydration by tube or drip and any other views they previously expressed about their care. The patient's request must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.
- 120** You must assess the patient's nutrition and hydration needs separately. If you judge that the provision of clinically assisted nutrition or hydration would not be of overall benefit to the patient, you may conclude that the treatment should not be started at that time or should be withdrawn. You should explain your view to the patient, if appropriate, and those close to them, and respond to any questions or concerns they express.
- 121** In these circumstances you must make sure that the patient's interests have been thoroughly considered. This means you must take all reasonable steps to get a second 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. This opinion should be based on an examination of the patient by the clinician. In exceptional circumstances, if this is not possible for practical reasons, you must still get advice from a colleague, for example by telephone, having given them up-to-date information about the patient's condition. You should also consider seeking legal advice.³⁵

- 122** If you reach a consensus that clinically assisted nutrition or hydration would not be of overall benefit to the patient and the treatment is withdrawn or not started, you must make sure that the patient is kept comfortable and that any distressing symptoms are addressed. You must monitor the patient's condition and be prepared to reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration in light of changes in their condition. If clinically assisted nutrition or hydration is started or reinstated after a later assessment, and you subsequently conclude that it would not be of overall benefit to continue with the treatment, you must seek a second opinion (or, if this is not possible, seek advice), following the advice in paragraph 121.

Adult patients who lack capacity and are expected to die within hours or days

- 123** If a patient is expected to die within hours or days, and you consider that the burdens of providing clinically assisted nutrition or hydration outweigh the benefits they are likely to bring, it will not usually be appropriate to

³⁵ You can discuss the options with your defence organisation or your employer's legal department. In Northern Ireland, where there is currently no primary legislation or relevant case law pertaining to the jurisdiction, it may be particularly important to do so before acting on decisions.

start or continue treatment. You must consider the patient's needs for nutrition and hydration separately.

- 124** If a patient has previously requested that nutrition or hydration be provided until their death, or those close to the patient are sure that this is what the patient wanted, the patient's wishes must be given weight and, when the benefits, burdens and risks are finely balanced, will usually be the deciding factor.
- 125** You must keep the patient's condition under review, especially if they live longer than you expected. If this is the case, you must reassess the benefits, burdens and risks of providing clinically assisted nutrition or hydration, as the patient's condition changes.

Patients in a persistent vegetative state (PVS) or similar condition

- 126** If you are considering withdrawing nutrition or hydration from a patient in PVS or a 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 ruling may be necessary in an individual case.

Conscientious objection

- 127** If you have a conscientious objection to withdrawing, or not providing, clinically assisted nutrition or hydration, you should follow the guidance in paragraphs 79-80.

Cardiopulmonary resuscitation (CPR)

128 When someone suffers sudden cardiac or respiratory arrest, CPR attempts to restart their heart or breathing and restore their circulation. CPR interventions are invasive and include chest compressions, electric shock by an external or implanted defibrillator, injection of drugs and ventilation. If attempted promptly, CPR has a reasonable success rate in some circumstances. Generally, however, CPR has a very low success rate and the burdens and risks of CPR include harmful side effects such as rib fracture and damage to internal organs; adverse clinical outcomes such as hypoxic brain damage; and other consequences for the patient such as increased physical disability. If the use of CPR is not successful in restarting the heart or breathing, and in restoring circulation, it may mean that the patient dies in an undignified and traumatic manner.

When to consider making a Do Not Attempt CPR (DNACPR) decision

129 If cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient dies in a dignified and peaceful manner. It may also help to ensure that the patient's last hours or days are spent in their preferred place of care by, for example, avoiding emergency admission from a community setting to hospital. These management plans are called Do Not Attempt CPR (DNACPR) orders, or Do Not Attempt Resuscitation or Allow Natural Death decisions.

- 130** In cases in which CPR might be successful, it might still not be seen as clinically appropriate because of the likely clinical outcomes. When considering whether to attempt CPR, you should consider the benefits, burdens and risks of treatment that the patient may need if CPR is successful. In cases where you assess that such treatment is unlikely to be clinically appropriate, you may conclude that CPR should not be attempted. Some patients with capacity to make their own decisions may wish to refuse CPR; or in the case of patients who lack capacity it may be judged that attempting CPR would not be of overall benefit to them. However, it can be difficult to establish the patient's wishes or to get relevant information about their underlying condition to make a considered judgement at the time they suffer a cardiac or respiratory arrest and an urgent decision has to be made. So, if a patient has an existing condition that makes cardiac or respiratory arrest likely, establishing a management plan in advance will help to ensure that the patient's wishes and preferences about treatment can be taken into account and that, if appropriate, a DNACPR decision is made and recorded.
- 131** If a patient is admitted to hospital acutely unwell, or becomes clinically unstable in their home or other place of care, and they are at foreseeable risk of cardiac or respiratory arrest, a judgement about the likely benefits, burdens and risks of CPR should be made as early as possible.^{xxix}

Discussions about whether to attempt CPR

- 132** As with other treatments, decisions about whether CPR should be attempted must be based on the circumstances and wishes of the individual patient. This may involve discussions with the patient or with those close to them, or both, as well as members of the healthcare team. You must approach discussions sensitively and bear in mind that some patients, or those close to them, may have concerns that decisions not to attempt CPR might be influenced by poorly informed or unfounded assumptions about the impact of disability or advanced age on the patient's quality of life.
- 133** If a patient lacks capacity to make a decision about future CPR, the views of members of the healthcare team involved in their care may be valuable in assessing the likely clinical effectiveness of attempting CPR and whether successful CPR is likely to be of overall benefit. You should make every effort to discuss a patient's CPR status with these healthcare professionals.

When CPR will not be successful

- 134** If a patient is at foreseeable risk of cardiac or respiratory arrest and you judge that CPR should not be attempted, because it will not be successful in restarting the patient's heart and breathing and restoring circulation, you must carefully consider whether it is necessary or appropriate to tell the patient that a DNACPR decision has been made. You should not make assumptions about a patient's wishes, but should explore in a sensitive way how willing they might be to know about a DNACPR decision. While some patients may want to be told, others may find discussion about

interventions that would not be clinically appropriate burdensome and of little or no value. You should not withhold information simply because conveying it is difficult or uncomfortable for you or the healthcare team.

- 135** If you conclude that the patient does not wish to know about or discuss a DNACPR decision, you should seek their agreement to share with those close to them, with carers and with others, the information they may need to know in order to support the patient's treatment and care.
- 136** If a patient lacks capacity, you should inform any legal proxy and others close to the patient about the DNACPR decision and the reasons for it.

When CPR may be successful

Patients who have capacity

- 137** If CPR may be successful in restarting a patient's heart and breathing and restoring circulation, the benefits of prolonging life must be weighed against the potential burdens and risks. But this is not solely a clinical decision. You should offer the patient opportunities to discuss (with support if they need it) whether CPR should be attempted in the circumstances that may surround a future cardiac or respiratory arrest. You must approach this sensitively and should not force a discussion or information onto the patient if they do not want it. However, if they are prepared to talk about it, you must provide them with accurate information about the burdens and risks of CPR interventions,^{xxx} including the likely clinical and other outcomes if CPR is successful. This should include sensitive explanation of the extent to which other intensive treatments and procedures may not be seen as

clinically appropriate after successful CPR. For example, in some cases, prolonged support for multi-organ failure in an intensive care unit may not be clinically appropriate even though the patient's heart has been restarted.

- 138** You should explain, in a sensitive manner, any doubts that you and the healthcare team may have about whether the burdens and risks of CPR would outweigh the benefits, including whether the level of recovery expected after successful CPR would be acceptable to the patient.
- 139** Some patients may wish to receive CPR when there is only a small chance of success, in spite of the risk of distressing clinical and other outcomes. If it is your considered judgement that CPR would not be clinically appropriate for the patient, you should make sure that they have accurate information about the nature of possible CPR interventions^{xxxi} and, for example, the length of survival and level of recovery that they might realistically expect if they were successfully resuscitated. You should explore the reasons for their request and try to reach agreement; for example, limited CPR interventions could be agreed in some cases. When the benefits, burdens and risks are finely balanced, the patient's request will usually be the deciding factor. If, after discussion, you still consider that CPR would not be clinically appropriate, you are not obliged to agree to attempt it in the circumstances envisaged. You should explain your reasons and any other options that may be available to the patient, including seeking a second opinion.

Patients who lack capacity

- 140** If a patient lacks capacity to make a decision about future CPR, you should consult any legal proxy who has authority to make the decision for the patient. If there is no legal proxy with relevant authority, you must discuss the issue with those close to the patient and with the healthcare team. In your consultations or discussions, you must follow the decision-making model in paragraph 16. In particular, you should be clear about the role that others are being asked to take in the decision-making process. If they do not have legal authority to make the decision, you should be clear that their role is to advise you and the healthcare team about the patient. You must not give them the impression that it is their responsibility to decide whether CPR will benefit, or be in the best interests of, the patient. You should provide any legal proxy and those close to the patient, with the same information about the nature of CPR and the burdens and risks for the patient as explained in paragraphs 137-138.
- 141** If the legal proxy requests that CPR with a small chance of success is attempted in future, in spite of the burdens and risks, or they are sure that this is what the patient wanted, and it is your considered judgement that CPR would not be clinically appropriate and not of overall benefit for the patient, you should explore the reasons for the proxy's request. If after further discussion you still consider that attempting CPR would not be of overall benefit for the patient, you are not obliged to offer to attempt CPR in the circumstances envisaged. You should explain your reasons and any other options that may be available to the legal proxy, including their right to seek a second opinion.

Resolving disagreements

- 142** If there is disagreement about whether CPR should be provided, you should try to resolve it by following the guidance in paragraphs 47-49.

Recording and communicating CPR decisions

- 143** Any discussions with a patient, or with those close to them, about whether to attempt CPR, and any decisions made, should be documented in the patient's record or advance care plan.³⁶ If a DNACPR decision is made and there has been no discussion with the patient because they indicated a wish to avoid it, or because it was your considered view that discussion with the patient was not appropriate, you should note this in the patient's records.

Treatment and care after a DNACPR decision

- 144** You must make it clear to the patient, to those close to them and to members of the healthcare team that a DNACPR decision applies only to CPR. It does not imply that other treatments will be stopped or withheld. Other treatment and care will be provided if it is clinically appropriate and agreed to by a patient with capacity, or if it is of overall benefit to a patient who lacks capacity.

³⁶ See the guidance on recording and communicating decisions in paragraphs 75-77.

- 145** A DNACPR decision should not override your clinical judgement about CPR if the patient experiences cardiac or respiratory arrest from a reversible cause, such as the induction of anaesthesia during a planned procedure, or if the circumstances of the arrest are not those envisaged when the DNACPR decision was made.

Emergencies and CPR

- 146** Emergencies can arise when there is no time to make a proper assessment of the patient's condition and the likely outcome of CPR; when no previous DNACPR decision is in place; and when it is not possible to find out 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.

References

- i The *Gold Standards Framework* 'prognostic indicator' is one example of a tool that helps with end of life prognosis (www.goldstandardsframework.nhs.uk and www.gsfs.scot.nhs.uk). See also the Northern Ireland Cancer Network (2008) *Diagnosing Dying – defining end of life care; supportive and palliative care network group* (www.cancerni.net).
- ii There are many publications on assessing and meeting patients' palliative care needs. Examples of national guidance include: *Changing Gear – guidelines for managing the last days of life in adults* (2006), National Council for Palliative Care; *Principles of Pain Control in Palliative Care for Adults*, Working Party report, Royal College of Physicians of London; *Control of Pain in Adults with Cancer*, Guideline 106 (2008), Scottish Intercollegiate Guideline Network; *Clinical practice guidelines for quality palliative care*, National consensus project for quality palliative care (Northern Ireland) (www.nationalconsensusproject.org).
- iii For information about patient and carer support and advocacy services, counselling and chaplaincy services and clinical ethics support networks, see the advice and resources listed at www.endoflifecareforadults.nhs.uk and at www.pallcareni.net
- iv Examples of national guidance about responses to resource issues include: *Supporting rational decision making about medicines (and treatments). A handbook of good practice* (First edition, Feb 2009), NHS National Prescribing Centre (www.npc.co.uk); *Guidance on NHS patients who wish to pay for additional private care* (March 2009), Department of Health (England) (www.dh.gov.uk).

- v Examples of resources that help doctors to address the health inequalities affecting some patient groups include: *Equal treatment: closing the gap. Information for practitioners* (2006) and *Supplement to Good Medical Practice* (2007) by the DRC and available from the Equality and Human Rights Commission (www.equalityhumanrights.com); *Living and dying with dignity – best practice guide to end of life care for people with a learning disability* (2008) Mencap (www.mencap.org.uk). See also the NHS national service frameworks for older people and children and young people.

- vi There are various publications setting out the benefits of advance care planning, examples include: *Joined up thinking. Joined up care. Increasing access to palliative care for people with life-threatening conditions other than cancer* (Nov 2006) by the Scottish Partnership for Palliative Care. The four UK governments have published national strategies and action plans to improve access to end of life and palliative care which discuss the role of advance care planning. See the *End of Life Care Strategy – Promoting High Quality Care for All Adults at the End of Life* (2008) DH, England (www.dh.gov.uk); *Living and Dying Well – A National Action Plan for End of Life Care in Scotland* (2008) by the Scottish Government (www.scotland.gov.uk); *Report to Minister for Health and Social Services on Palliative Care Services* (2008) (www.wales.nhs.uk); *Living Matters. Dying Matters: A Palliative and End of Life Care Strategy for Adults in Northern Ireland* (2010) DHSSPS (www.pallcareni.net).

- vii A number of reports have been published about the needs and preferences of particular patient groups in relation to end of life treatment and care. Examples include: *Dying in older age: reflections and experiences from an older person's perspective* (2005) by Help the Aged (www.helptheaged.org.uk); *Ethnicity, Older People and Palliative Care* (2006) by National

- Council for Palliative Care and the Policy Research Institute on Ageing and Ethnicity, London; *An ordinary death: the service needs of people with learning disabilities who are dying* (2003) by the Foundation for People with Learning Disabilities (www.learningdisabilities.org.uk); *Better care. Better lives. Improving outcomes for children and young people and their families living with life-limiting and life-threatening conditions* (2008) DH England (www.dh.gov.uk).
- viii Examples of national guidance on how to approach advance care planning include: *Advance care planning: national guidelines* (2009) Royal College of Physicians of London; *Advance care planning: a guide for health and social care staff* (Aug 2008) (www.endoflifecareforadults.nhs.uk); *Ascertaining wishes: a good practice guide. Advance care planning for care homes for older people* is available from Counsel and Care (www.counselandcare.org.uk). The BMA has published guidance covering this and other issues in end of life treatment and care in *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making* (2007) (www.bma.org.uk).
- ix Advice for doctors and patients about making formal records of advance refusals of treatment is available from the Advance Decisions to Refuse Treatment website (www.adrtnhs.co.uk); the Office of the Public Guardian (England and Wales) (www.publicguardian.gov.uk) and in Scotland (www.publicguardian-scotland.gov.uk); and the Mental Welfare Commission for Scotland (www.mwcs.org.uk). Many patient support organisations also provide advice. The BMA has published guidance for doctors in *Advance decisions and proxy decision making in medical treatment and research* (2007) (www.bma.org.uk).

- x The *Gold Standards Framework* is one tool used to improve collaboration among care homes, GPs, primary care teams and specialist palliative care teams, and to reduce the number of admissions to hospital in the last days of life. It is available at www.goldstandardsframework.nhs.uk and at www.gsfs.scot.nhs.uk. *Teams without Walls* (2008) is a report by the Royal Colleges of Physicians, Paediatrics and Child Health and GPs with advice on integrating services (www.rcplondon.ac.uk). See also the *Out-of-hours toolkit* developed by Macmillan Cancer Care (www.learnzone.macmillan.org.uk).
- xi Collaboration across different health and social care settings may be helped by current or planned introduction of 'locality registers' for patients receiving end of life care in England; e-palliative care records in Scotland; and the proposed e-record in Northern Ireland.
- xii Structured decision making and review of a patient's care in the last days of life can be supported by tools such as the *Liverpool Care Pathway* which is available at www.mcpcil.org.uk and www.endoflifecareforadults.nhs.uk; and the *All Wales Care Pathway for the Last days of Life*, Welsh Assembly Government, in Welsh Health Circular (2006) 030.
- xiii Patients may have recorded their wishes about organ or tissue donation in the NHS Organ Donor Register held by NHS Blood and Transplant (www.nhsbt.nhs.uk). Guidance on the issues that may be of concern to families can be found in publications such as *Donor Family Care Policy* (2004) and *Organ donation and religious perspectives* (2010) by NHS Blood and Transplant.
- xiv See publications on *Donor Family Care Policy* (2004) and *Organ donation and religious perspectives* (2010), and other guides from NHS Blood and Transplant at www.nhsbt.nhs.uk

- xv See the *Human Tissue Act 2004* and *Human Tissue (Scotland) Act 2006*.
- xvi *Human Tissue Authority Code of Practice 1: Consent (2009)*, *Code of Practice 2: Donation of solid organs for transplantation (2009)* (www.hta.gov.uk).
- xvii The *Liverpool Care Pathway* is one source of advice on meeting the spiritual and other personal needs of patients and their carers in the last days of life and into bereavement. It is available at www.endoflifecareforadults.nhs.uk. See also the *All Wales Care Pathway for the Last Days of Life*. Welsh Assembly Government, in Welsh Health Circular (2006) 030. Advice is also available from the Multi-faith Group for Healthcare Chaplaincy (www.mfghc.com).
- xviii Help in supporting bereaved adults and children is available from a number of sources, including the Child Bereavement Charity (www.childbereavement.org.uk); Cruse Bereavement Care (www.crusebereavementcare.org.uk) and Cruse Scotland (www.crusescotland.org.uk).
- xix Information and guidance on the statutory requirements for completing death and cremation certificates is available from a number of sources including: Home Office *Guidance for doctors completing Medical Certificates of Cause of Death in England and Wales* (www.gro.gov.uk/medcert/); Ministry of Justice *Cremation Regulations Guidance for doctors (2008)* (www.justice.gov.uk); Scottish *Guidance on completion of medical certificates of the cause of death (Sep 2009)* ([www.sehd.scot.nhs.uk/cmo/CMO\(2009\)10.pdf](http://www.sehd.scot.nhs.uk/cmo/CMO(2009)10.pdf)). Northern Ireland *Guidance on death, stillbirth and cremation certification* is available at www.dhsspsni.gov.uk and information for families *Registering a death* can be found at www.groni.gov.uk

- xx Comprehensive information for professionals and parents about certifying the death of a baby can be found in *Pregnancy, loss and the death of a baby* by SANDS, the stillbirth and neonatal death charity (www.uk-sands.org). Guidance to support practitioners in speaking to a patient's family is also available from a range of organisations, including the General Register Offices.
- xxi Human Tissue Authority *Code of practice 3: Post-mortem examination* (www.hta.gov.uk). The Crown Office and Procurator Fiscal Service (Scotland) advice on post-mortems (www.copfs.gov.uk). Ministry of Justice *A guide to coroners and inquests* (Jan 2010) (www.justice.gov.uk).
- xxii There are many sources of advice, and examples of national guidelines include: *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); Nuffield Council on Bioethics *Critical care decisions in fetal and neonatal medicine: ethical issues* (November 2006) (www.nuffieldbioethics.org).
- xxiii Examples of national guidelines on end of life treatment and care for children and young people include: *Withholding and withdrawing life-sustaining treatment in children. A framework for practice* (2nd edition 2004 – currently under review). Royal College of Paediatrics and Child Health (www.rcpch.ac.uk). BMA (3rd edition 2007) *Withholding and withdrawing life-prolonging medical treatment: guidance for decision making*. See Part 7: Decision making by young people with capacity (pp 83-95) and Part 8: Decision making for children and young people who lack capacity (pp 96-108). See also the NHS *Toolkit for high quality neonatal services* (2009) (www.dh.gov.uk).

- xxiv Parent support organisations such as Bliss (www.bliss.org.uk), Tiny Life (www.tinylife.org.uk) and Cerebra (www.cerebra.org.uk) publish leaflets and give telephone support. See for example the Bliss leaflet *Helping you with intensive care decisions for your baby* (2010).
- xxv For information about organisations providing advocacy and support for children and parents see *Advocating for children* (January 2009) by the Royal College of Paediatrics and Child Health (www.rcpch.ac.uk). Patient Advice and Liaison services (England) provide support, advice and mediation for children, parents and other carers. Help is available from Community Health Councils (Wales) (www.communityhealthcouncils.org.uk). For information on independent advocacy in Scotland visit Partners in Advocacy (www.partnersinadvocacy.org.uk). For Northern Ireland children's advocacy services visit www.niccy.org. Children First for Health is an NHS online resource to help children and parents share their experiences and get information (www.childrenfirst.nhs.uk).
- xxvi NICE guideline *Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition* (Feb 2006) (www.nice.org.uk). 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). *Oral feeding difficulties and dilemmas: A guide to practical care, particularly towards the end of life* (Jan 2010) Royal College of Physicians, co-published with the British Society of Gastroenterology (www.rcplondon.ac.uk).
- xxvii An explanation of the different techniques for providing nutrition and hydration by tube or drip can be found in the NICE guideline *Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral*

nutrition. (Feb 2006). *Artificial Nutrition and Hydration: guidance in end of life care for adults*. National Council for Palliative Care (2007).

- xxviii For a detailed discussion of evidence on the benefits, burdens and risks when nutrition or hydration is provided by drip or tube, refer to *Improving Nutritional Care. A joint action plan from the Department of Health and Nutrition Summit stakeholders* (October 2007) (www.dh.gov.uk).
- xxix Advice for clinicians on when to attempt to resuscitate, and when it is appropriate not to do so, is available from specialist bodies, for example in *Cardiopulmonary resuscitation – standards for clinical practice and training* a 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; *Decisions relating to cardiopulmonary resuscitation. A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing* (October 2007) available at www.bma.org.uk; *Integrated policy on Do Not Attempt Cardio-pulmonary Resuscitation* (2010) NHS Scotland.
- xxx There are many patient guides on CPR including guidance published by the Resuscitation Council UK which gives details about immediate and advance resuscitation for adults, and about paediatric and newborn life support. A *model patient information leaflet* is available from their website www.resus.org.uk. See also *Decisions about resuscitation. Information for patients, their relatives and carers* (2010) NHS Scotland.
- xxxi The Liverpool Care Pathway is one evidence base for the effectiveness of CPR in the last days of life (available at www.mcpcil.org.uk and www.endoflifecareforadults.nhs.uk).

Legal annex

This annex is not intended to be a comprehensive statement of the law or a 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 that relates 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

The capacity legislation

The guidance draws special attention to the *Mental Capacity Act 2005* (England and Wales) and its Code of Practice, and the *Adults with Incapacity (Scotland) Act 2000* and its Code of Practice. The two Acts 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 decisions.
- How adults can make provision for future decisions by appointing attorneys; by recording statements of their preferences; and by making advance decisions to refuse treatment.
- Statutory principles that must guide those making decisions on behalf of an adult who lacks capacity.
- Requirements for supporting adults who lack capacity or who have impaired capacity to make decisions, including the appointment of independent advocates.
- Factors to consider when assessing a person's capacity to make a particular decision, including their ability to communicate.

- Factors to take into account in reaching a judgement about what course of action would be of benefit to the person, or in the person's best interests, if an adult lacks capacity to decide. This includes advice on 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 their liberty.
- Processes for resolving disagreements (statutory requirements in Scotland) and for making referrals to the court, if necessary.

It is important that doctors who work in England, Wales and Scotland are familiar with the statutory principles set out in the capacity legislation as these must be taken into account in health and social care decisions made on behalf of adults who lack capacity. It is also important that doctors are familiar with key requirements in the relevant Act and supporting Code of Practice.

The *Mental Capacity Act 2005* Code of Practice is a statutory code that doctors are expected to observe in their day-to-day treatment and care of adults who lack capacity to make a decision. There are details of the Act and Code, and access to training materials and guidance, on the websites of the Department of Health (DH) England, the Welsh Assembly, and the Office of the Public Guardian. Advice and support in working with the Act and Code in health and social care settings are currently available from Implementation Leads in NHS trusts and health boards. There is 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 *Adults with Incapacity (Scotland) Act* Code of Practice (part 5: decisions about medical treatment and research) provides guidance on applying the Act. Doctors are expected to take this guidance 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 guidance is published by the Mental Welfare Commission which also gives advice on working with the Act and Code.

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

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

In Northern Ireland, it is important that doctors are aware of current proposals to introduce in 2011 a draft Bill governing decision making in relation to adults who lack mental capacity and the compulsory treatment of mental health conditions.

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 ECHR 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 ECHR 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.¹ 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 that 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 a definitive statement of the case law, and we do not use the same terminology as appears in the court judgments. The endnotes contain the case references.

- An act by which the doctor's primary intention² is to bring about a patient's death would be unlawful.³
- An adult patient who has capacity may decide to refuse treatment even if refusal may result in harm to themselves or in their own death.⁴ 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.⁵ Doctors are bound to respect a refusal of treatment from a patient who has capacity and, if they have an objection to the refusal, they have a duty to find another doctor who will carry out the patient's wishes.⁶
- Life prolonging treatment can lawfully be withheld or withdrawn from a patient who lacks capacity when starting or continuing treatment is not in their best interests.⁷
- There is no obligation to give treatment that is futile or burdensome.⁸
- If an adult patient has lost capacity, a refusal of treatment they made when they had capacity must be respected, provided it is clearly applicable to the present circumstances and there is no reason to believe that the patient had had a change of mind.⁹
- In the case of children or adults who lack capacity to decide, when 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 that treatment may be one of the appropriate considerations.¹⁰

- 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.¹¹
- A patient's best interests may be interpreted as meaning that a patient should not be subjected to more treatment than is necessary to allow them to die peacefully and with dignity.¹²
- All reasonable steps should be taken to overcome challenges when communicating with, or managing the care of patients with disabilities, to ensure that they are provided with the treatment they need and that would be in the best interests of the patient.¹³
- If clinicians and a child's family are in fundamental disagreement over the child's treatment, the views of the court should be sought.¹⁴
- If a patient asks for a treatment that their doctor has not offered, and the doctor concludes that the treatment will not be clinically appropriate to the patient, the doctor is not obliged to provide it, but they should offer to arrange for a second opinion.¹⁵
- If clinically assisted nutrition or hydration is necessary to keep a patient alive, the duty of care will normally require the doctor to provide it, if a patient with capacity wishes to receive it.¹⁶
- Clinically assisted nutrition or hydration may be withheld or withdrawn if the patient does not wish to receive it; or if the patient is dying and the care goals change to palliative care and relief of suffering; or if the patient lacks capacity to decide and it is considered that providing clinically assisted nutrition or hydration would not be in their best interests.¹⁷
- In the case of patients in a permanent vegetative state (PVS), clinically assisted nutrition or hydration constitutes medical treatment and may be lawfully withdrawn in certain circumstances.¹⁸ However, in practice, a court declaration should be obtained.¹⁹

- Responsibility rests with the doctor to decide which treatments are clinically indicated and should be offered to the patient. The decision to provide treatment should be subject to the patient's consent if they have capacity or, if they lack capacity, any known views of the patient prior to losing capacity and any views offered by those close to them.²⁰
- 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 best interests.²¹

In this area, although case law in Scotland and Northern Ireland has not been much developed, generally the courts in Scotland can be expected to follow the English decisions. In Northern Ireland, decisions of the House of Lords are binding on the courts; decisions of the Court of Appeal in England are regarded as highly persuasive; and decisions of the High Court in England are read with interest and often followed.

Endnotes for Legal Annex

- 1 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.
- 2 R v Cox (1992) 12 BMLR 38.
- 3 For a very rare exception in the case of conjoined twins see Re: A (Children) (Conjoined twins: surgical separation) [2000] 4 All ER 961.
- 4 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.
- 5 St George's Healthcare Trust v S (No 2). R v Louise Collins & Others, Ex Parte S (No 2) [1993] 3 WLR 936.
- 6 Re Ms B v a NHS Hospital Trust [2002] EWHC 429 (Fam).
- 7 Airedale NHS Trust v Bland [1993] 1 All ER 821.
- 8 Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930.
- 9 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.
- 10 Re B [1981] 1 WLR 421; Re C (A Minor) [1989] 2 All ER 782; Re J (A Minor) (Wardship: Medical Treatment) [1990] 3 All ER 930; Re R (Adult: Medical Treatment) [1996] 2 FLR 99.
- 11 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).
- 12 An NHS Trust v Ms D [2005] EWHC 2439 (Fam). Burke v GMC [2005] EWCA Civ 1003.
- 13 An NHS Trust v S & Ors [2003] EWHC 365 (Fam).
- 14 Glass v the United Kingdom (ECHR, 2004).

- 15 Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614; Burke v GMC [2005] EWCA Civ 1003.
- 16 Burke v GMC [2005] EWCA Civ 1003.
- 17 Burke v GMC [2005] EWCA Civ 1003. NHS Trust v Ms D [2005] EWHC 2439 (Fam).
- 18 Airedale NHS Trust v Bland [1993] 1 All ER 821; Law Hospital NHS Trust v Lord Advocate 1996 SLT 848.
- 19 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.
- 20 Re J (A Minor) (Child in Care: Medical Treatment) [1992] 2 All ER 614; and Re G (Persistent Vegetative State) [1995] 2 FCR 46.
- 21 Re A (Male Sterilisation) [2000] FCR 193; and Re S (Adult: Sterilisation) [2000] 2 FLR 389. Health And Social Services Trust v PM & Anor [2007] NIFam 13 (21 December 2007).

Glossary of terms

Advance care planning: The process of discussing the type of treatment and care that a patient would or would not wish to receive in the event that they lose capacity to decide or are unable to express a preference, for example their preferred place of care and who they would want to be involved in making decisions on their behalf. It seeks to create a record of a patient's wishes and values, preferences and decisions, to ensure that care is planned and delivered in a way that meets their needs and involves and meets the needs of those close to the patient.

Advance decision or advance directive: A statement of a patient's wish to refuse a particular type of medical treatment or care if they become unable to make or communicate decisions for themselves. They are called advance decisions in England and Wales, and advance directives in Scotland. If an advance refusal is valid and applicable to the person's current circumstances, it must be respected. It will be legally binding on those providing care in England and Wales (provided that if it relates to life-prolonging treatment it satisfies the additional legal criteria), and it is likely to be legally binding in Scotland and Northern Ireland.

Advance statement: A statement of a patient's views about how they would or would not wish to be treated if they become unable to make or communicate decisions for themselves. This can be a general statement about, for example, wishes regarding place of residence, religious and cultural beliefs, and other personal values and preferences, as well as about medical treatment and care.

Artificial nutrition and hydration (ANH): See clinically assisted nutrition and hydration.

Capacity: The ability to make a decision. An adult is deemed to have capacity unless, having been given all appropriate help and support, it is clear that they cannot understand, retain, use or weigh up the information needed to make a particular decision or to communicate their wishes.

Clinically assisted nutrition and hydration (CANH): Clinically assisted nutrition includes nasogastric feeding and percutaneous endoscopic gastrostomy (PEG) or radiologically inserted gastrostomy (RIG) feeding tubes through the abdominal wall. PEG, RIG and nasogastric tube feeding also provide fluids necessary to keep patients hydrated. Clinically assisted hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), and nasogastric tube feeding or administration of fluid. The term 'clinically assisted nutrition and hydration' does not refer to help given to patients to eat or drink, for example spoon feeding.

Clinician: A health professional, such as a doctor or nurse, involved in clinical practice.

DNACPR: Abbreviation of 'Do Not Attempt Cardiopulmonary Resuscitation'. These advance management plans may be called DNAR orders or Allow Natural Death decisions in some healthcare settings.

End of life: Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes those patients whose death is expected within hours or days; those who have advanced, progressive incurable conditions; those with general frailty and co-existing conditions that mean they are expected to die within 12 months; those at risk of dying from a sudden acute crisis in an existing condition; and those with life-threatening acute conditions caused by sudden catastrophic events. The term 'approaching the end of life' can also apply

to extremely premature neonates whose prospects for survival are known to be very poor, and patients who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment and care may lead to their death.

End stage: The final period or phase in the course of a progressive disease leading to a patient's death.

Legal proxy: A person with legal authority to make certain decisions on behalf of another adult. Legal proxies who can make healthcare decisions include: a person holding a Lasting Power of Attorney (England and Wales) or a Welfare Power of Attorney (Scotland); a court appointed deputy (England and Wales); and a court appointed guardian or court appointed intervener (Scotland). Northern Ireland currently has no provision for appointing legal proxies with the power to make healthcare decisions.

Neonates: Newborn infants (less than one month old).

Overall benefit: In this guidance the term 'overall benefit' describes the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide. It involves an assessment of the appropriateness of treatment and care options that encompasses not only the potential clinical benefits, burdens and risks of those options, but also non-clinical factors such as the patient's personal circumstances, wishes, beliefs and values. GMC guidance on overall benefit, applied with the decision-making principles in paragraphs 7-13, is consistent with the legal requirement to consider whether treatment 'benefits' a patient (Scotland), or is in the patient's 'best interests' (England, Wales and Northern Ireland), and to apply the other principles set out in the *Mental Capacity Act 2005* and the *Adults with Incapacity (Scotland) Act 2000*.

Palliative care: The holistic care of patients with advanced, progressive, incurable illness, focused on the management of a patient's pain and other distressing symptoms and the provision of psychological, social and spiritual support to patients and their family. Palliative care is not dependent on diagnosis or prognosis, and can be provided at any stage of a patient's illness, not only in the last few days of life. The objective is to support patients to live as well as possible until they die and to die with dignity.

Persistent vegetative state (PVS): Also termed a 'permanent vegetative state'. An irreversible condition resulting from brain damage, characterised by lack of consciousness, thought, and feeling, although some reflex activities, such as breathing, continue.

Second opinion: An independent opinion from a senior clinician (who might be from another discipline) who has experience of the patient's condition but who is not directly involved in the patient's care. A second opinion should be based on an examination of the patient by the clinician.

Those close to the patient: Anyone nominated by the patient, close relatives (including parents if the patient is a child), partners, close friends, paid or unpaid carers outside the healthcare team, and independent advocates. It may include attorneys for property and financial affairs and other legal proxies, in some circumstances.

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