

# Reference guide to consent for examination or treatment

*Second edition*



**DH INFORMATION READER BOX**

<b>Policy</b> HR/Workforce Management Planning Clinical	Estates Commissioning IM & T Finance Social Care/Partnership Working
<b>Document purpose</b>	For information
<b>Gateway reference</b>	11911
<b>Title</b>	Reference guide to consent for examination or treatment, second edition 2009
<b>Author</b>	Department of Health
<b>Publication date</b>	July 2009
<b>Target audience</b>	PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Medical Directors, Directors of PH, Directors of Nursing, Local Authority CEs, Directors of Adult Ss, Special HA CEs, Allied Health Professionals, GPs, Emergency Care Leads, Directors of Children's Ss
<b>Circulation list</b>	
<b>Description</b>	This document updates that issued in 2001 and provides a guide to the legal framework that all health professionals need to take account of in obtaining valid consent for any examination, treatment or care that they propose to undertake.
<b>Cross reference</b>	See <a href="http://www.dh.gov.uk/consent">www.dh.gov.uk/consent</a>
<b>Superseded documents</b>	Reference Guide to Consent for Examination or Treatment (first edition, March 2001)
<b>Action required</b>	N/A
<b>Timing</b>	N/A
<b>Contact details</b>	Marjorie Thorburn Health, Science and Bioethics Division Room 611, Wellington House 133-155 Waterloo Road London SE1 8UG 020 7972 4758  <a href="http://www.dh.gov.uk/consent">www.dh.gov.uk/consent</a>
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First published July 2009

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# Reference guide to consent for examination or treatment

*Second edition*



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# Executive summary

1. This booklet provides a guide to English law concerning consent to physical examination or treatment. This second edition provides an update on legislation relating to obtaining valid consent – the Human Tissue Act 2004, the Mental Capacity Act 2005 and recent legal cases – and provides references where appropriate.
2. The guide describes the process of seeking consent, the importance of establishing whether the person has capacity to give consent, what constitutes valid consent, the form that consent might take and the duration of that consent. It highlights the need to ensure that the consent is given voluntarily and that sufficient information has been imparted to allow valid consent to be made. It deals with consent issues arising from additional procedures that may be required during treatment and are not covered by the original consent, consent relating to the subsequent use of removed tissue, consent to visual and audio recordings, the requirements concerning gametes and the requirements for living donation and for research and innovative treatment.
3. The Mental Capacity Act now puts advance decisions on a statutory basis. This guide clearly sets out that healthcare professionals must follow an advanced decision where it is valid and applicable, what they must consider if it is not valid and what they must consider if they disagree with a person's right to refuse life-sustaining treatment. The guide also addresses the difficult issues around self-harm where an assessment of a person's mental capacity is a key aspect.
4. The Mental Capacity Act 2005 applies in England and Wales to all those working in health and social care involved in the care, treatment and support of those aged 16 or over who may lack the capacity to make decisions for themselves. This guide provides a synopsis of the main provisions of the Act and sets out how 'best interests' decisions need to be made for those lacking capacity. The guide refers readers to the Mental Capacity Act Code of Practice for detailed guidance, and includes a brief guide to some important aspects such as the duration of the lack of capacity, the need to consider a person's statement of preferences and wishes, lasting power of attorney, court appointed deputies, independent mental capacity advocates and the Court of Protection.
5. The legal position concerning consent and refusal of treatment by those under the age of 18 is also described, as this is different from that of adults. In the guide, 'children' refers to people below the age of 16 and 'young people' refers to people aged 16–17.

Reference is made to 'Gillick competence' and the detail of how consent decisions may be made for children lacking capacity (ie those who are not Gillick competent) is given.

6. The guide sets out the legal principles around consent decisions relating to the withdrawing or withholding of life-sustaining treatment. It describes the position for adults and children with capacity separately from adults and children lacking capacity.
7. The guide concludes by briefly referring to specific statutes that provide some exceptions to the principles described, such as the Mental Health Act 1983 which sets out circumstances in which persons liable to be detained under that Act may be treated without consent for their mental disorder.

# Introduction

1. It is a general legal and ethical principle that valid consent must be obtained before starting treatment or physical investigation, or providing personal care, for a person. This principle reflects the right of patients to determine what happens to their own bodies, and is a fundamental part of good practice. A healthcare professional (or other healthcare staff) who does not respect this principle may be liable both to legal action by the patient and to action by their professional body. Employing bodies may also be liable for the actions of their staff.
2. While there is no English statute setting out the general principles of consent, case law ('common law') has established that touching a patient without valid consent may constitute the civil or criminal offence of battery. Further, if healthcare professionals (or other healthcare staff) fail to obtain proper consent and the patient subsequently suffers harm as a result of treatment, this may be a factor in a claim of negligence against the healthcare professional involved. Poor handling of the consent process may also result in complaints from patients through the NHS complaints procedure or to professional bodies.
3. This document provides guidance on English law concerning consent to physical interventions on patients – from major surgery and the administration or prescription of drugs to assistance with dressing – and is relevant to all healthcare practitioners (including students) who carry out interventions of this nature. It updates previous guidance issued in 2001, which was prepared with the assistance of the Good Practice in Consent Advisory Group,<sup>1</sup> in order to reflect recent legislative changes. Guidance is provided on the legal requirements for obtaining valid consent and on the situations where the law recognises exceptions to the requirement to obtain consent. References to the cases on which this guidance is based are given in footnotes. It should be noted that this guidance is specific to consent for physical interventions involving living patients, and the following areas are therefore not included:
  - participation in observational studies
  - the use of personal information
  - the use of organs or tissue after death (see paragraph 7 of this introduction).

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<sup>1</sup> Details of the Good Practice in Consent Advisory Group and the previous guidance and an electronic version of this guidance are available at [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)

4. Case law on consent has evolved significantly over recent years. Further legal developments may occur after this guidance has been issued, and all healthcare practitioners must remember their duty to keep themselves informed of legal developments that may have a bearing on their practice. Legal advice should always be sought if there is any doubt about the legal validity of a proposed intervention. While much of the case law refers specifically to doctors, the same principles will apply to other healthcare practitioners involved in examining or treating patients.
5. The Human Rights Act 1998 came into force in October 2000, giving further effect in the UK to the rights enshrined in the European Convention on Human Rights. All public authorities are required to act in accordance with the rights set out in the Human Rights Act, and all other statutes have to be interpreted by the courts so far as possible in accordance with those rights. The main articles that are likely to be relevant in medical case law are Article 2 (protection of the right to life), Article 3 (prohibition of torture and inhuman or degrading treatment or punishment), Article 5 (the right to liberty and security), Article 8 (the right to respect for private and family life), Article 9 (freedom of thought, conscience and religion), Article 12 (the right to marry and found a family) and Article 14 (prohibition of discrimination in the enjoyment of Convention rights).
6. Compliance with the Human Rights Act is largely reflected in existing good ethical practice, but all health practitioners should be aware of the Human Rights Act and ensure that they act in compliance with it. The British Medical Association (BMA) has a handbook of ethics and law that gives advice on how the Human Rights Act relates to a range of relevant issues.<sup>2</sup>

## Recent developments

7. The Human Tissue Act 2004 came fully into force on 1 September 2006.<sup>3</sup> It sets out the legal framework for the storage and use of tissue from the living and for the removal, storage and use of tissue and organs from the dead, including 'residual' tissue following clinical and diagnostic procedures. The Human Tissue Act makes consent a legal requirement for the removal, storage and use of human tissue or organs and sets out whose consent is needed in which circumstances. The Act also established the Human Tissue Authority (HTA). The HTA is also responsible for approving the transplantation of organs from living donors and bone marrow and peripheral blood stem cells from adults who lack the capacity to consent and children who lack

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2 BMA (2004) *Medical Ethics Today: The BMA's Handbook of Ethics and Law (second edition)*. London: BMJ Group

3 [www.opsi.gov.uk/acts/acts2004/ukpga\\_20040030\\_en\\_1](http://www.opsi.gov.uk/acts/acts2004/ukpga_20040030_en_1)

the competence to consent. Further guidance on consent and codes of practice are available on the HTA's website.<sup>4</sup>

8. The Mental Capacity Act 2005,<sup>5</sup> which came fully into force on 1 October 2007, sets out a statutory framework for making treatment decisions for people who lack the capacity to make such decisions themselves (see chapter 2). The Act establishes overarching statutory principles governing these decisions, setting out who can make them and when. It sets out the legal requirements for assessing whether or not a person lacks the capacity to make a decision.
9. Where a person lacks the capacity to make a decision for themselves, any decision must be made in that person's best interests. The Mental Capacity Act introduced a duty on NHS bodies to instruct an independent mental capacity advocate (IMCA) in serious medical treatment decisions when a person who lacks the capacity to make a decision has no one who can speak for them, other than paid staff. The Act allows people to plan ahead for a time when they may not have the capacity to make their own decisions: it allows them to appoint a personal welfare attorney to make health and social care decisions, including medical treatment, on their behalf or to make an advance decision to refuse medical treatment.
10. Further guidance is available in the Mental Capacity Act (2005) Code of Practice.<sup>6</sup>
11. There have been a number of recent legal cases that health professionals should be aware of:
  - *Ms B v An NHS Hospital Trust*.<sup>7</sup> Following an illness, Ms B became tetraplegic and reliant on an artificial ventilator. She asked that the ventilator that was keeping her alive be switched off, and claimed that the continued provision of artificial ventilation against her wishes was an unlawful trespass. The court was asked to decide whether Ms B had the capacity to make the decision about whether the ventilator should be removed. The Court held that Ms B did have capacity to refuse treatment and had therefore been treated unlawfully. Where a patient has the capacity to make decisions about treatment, they have the right to refuse treatment – even when the consequences of such decisions could lead to their death. If a doctor feels unable to carry out the wishes of the patient, their duty is to find another doctor who will do so.

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4 [www.hta.gov.uk](http://www.hta.gov.uk)

5 [www.opsi.gov.uk/acts/acts2005/ukpga\\_20050009\\_en\\_1](http://www.opsi.gov.uk/acts/acts2005/ukpga_20050009_en_1)

6 [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

7 *Ms B v An NHS Hospital Trust* [2002] 2 All ER 449

- *Glass v United Kingdom* (see chapter 3, paragraph 21).<sup>8</sup> The European Court of Human Rights held that a decision of health professionals to override the wishes of the mother of a seriously ill child gave rise to a breach of Article 8 of the European Convention on Human Rights. The court was critical of the fact that the courts were not involved at an earlier stage, and held that, in the event of a continued disagreement between parents and doctors about a child's treatment, the courts should be consulted, and particularly before the matter reaches an emergency situation.
  - *Chester v Afshar* (see chapter 1, paragraph 17).<sup>9</sup> The House of Lords judgment held that a failure to warn a patient of a risk of injury inherent in surgery, however small the probability of the risk occurring, denies the patient the chance to make a fully informed decision. The judgment held that it is advisable that health practitioners give information about all significant possible adverse outcomes and make a record of the information given.
  - *Burke v the General Medical Council* (see chapter 4, paragraph 7).<sup>10</sup> The Court of Appeal held that the General Medical Council (GMC) guidance on withholding and withdrawing life-prolonging treatment was lawful. A patient cannot demand a particular treatment, but health professionals must take account of a patient's wishes when making treatment decisions. Where a patient with capacity indicates his or her wish to be kept alive by the provision of Artificial Nutrition and Hydration (ANH), the doctor's duty of care will require the doctors to provide ANH for as long as such treatment continues to prolong life. Where life depends upon the continued provision of ANH, ANH will be clinically indicated. A health professional who deliberately brought that patient's life to an end by withdrawing ANH would be in breach of their duty of care and guilty of murder. If the patient lacks capacity, all reasonable steps that are in the person's best interests should be taken to prolong their life. Although there is a strong presumption in favour of providing life-sustaining treatment, there are circumstances when continuing or providing life-sustaining treatment stops providing a benefit to a patient and is not clinically indicated.
12. The standards expected of healthcare professionals by their regulatory bodies may at times be higher than the minimum required by the law. Although this guidance focuses primarily on the legal position, it will also indicate relevant guidance from regulatory bodies. It should be noted that the legal requirements in negligence cases have historically been based on the standards set by the professions for their members; therefore where the standards required by professional bodies are rising, it is likely that the legal standards will rise accordingly.

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<sup>8</sup> *Glass v United Kingdom* (61827/00) [2004] 1 FLR 1019 European Court of Human Rights

<sup>9</sup> *Chester v Afshar* [2004] UKHL 41

<sup>10</sup> *Burke v the General Medical Council* [2005] 3 WLR 1132

# 1 Seeking consent

## Valid consent

1. For consent to be valid, it must be given voluntarily by an appropriately informed person who has the capacity to consent to the intervention in question (this will be the patient or someone with parental responsibility for a patient under the age of 18,<sup>11</sup> someone authorised to do so under a Lasting Power of Attorney (LPA) or someone who has the authority to make treatment decisions as a court appointed deputy<sup>12</sup>). Acquiescence where the person does not know what the intervention entails is not ‘consent’.

## Does the person have capacity?

2. The Mental Capacity Act 2005 defines a person who lacks capacity as a person who is unable to make a decision for themselves because of an impairment or disturbance in the functioning of their mind or brain. It does not matter if the impairment or disturbance is permanent or temporary. A person lacks capacity if:
  - they have an impairment or disturbance (for example a disability, condition or trauma or the effect of drugs or alcohol) that affects the way their mind or brain works, and
  - that impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made.
3. An assessment of a person’s capacity must be based on their ability to make a specific decision at the time it needs to be made, and not their ability to make decisions in general. A person is unable to make a decision if they cannot do one or more of the following things:
  - understand the information given to them that is relevant to the decision
  - retain that information long enough to be able to make the decision
  - use or weigh up the information as part of the decision-making process
  - communicate their decision – this could be by talking or using sign language and includes simple muscle movements such as blinking an eye or squeezing a hand.

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11 See chapter 3

12 See chapter 2

4. People may have capacity to consent to some interventions but not to others, or may have capacity at some times but not others. Under the Mental Capacity Act, a person must be assumed to have capacity unless it is established that they lack capacity. If there is any doubt, then the healthcare professional should assess the capacity of the patient to take the decision in question. This assessment and the conclusions drawn from it should be recorded in the patient's notes. Guidance on assessing capacity is given in chapter 4 of the Mental Capacity Act (2005) Code of Practice.<sup>13</sup>
5. A person's capacity to consent may be temporarily affected by factors such as confusion, panic, shock, fatigue, pain or medication. However, the existence of such factors should not lead to an automatic assumption that the person does not have the capacity to consent.
6. Capacity should not be confused with a healthcare professional's assessment of the reasonableness of the person's decision. Under the Mental Capacity Act and the common law, a person is not to be treated as unable to make a decision merely because they make an unwise decision. A person is entitled to make a decision which may be perceived by others to be unwise or irrational, as long as they have the capacity to do so.
7. However, if the decision that appears irrational is based on a misperception of reality, as opposed to a different value system to that of the health practitioner – for example a patient who, despite the obvious evidence, denies that his foot is gangrenous, or a patient with anorexia nervosa who is unable to comprehend their failing physical condition – then the patient may not be able to comprehend, weigh or make use of the relevant information and hence may lack the capacity to make the decision in question.
8. The Mental Capacity Act also requires that all practical and appropriate steps are taken to enable a person to make the decision themselves. These steps include the following:
  - Providing relevant information. For example, if there is a choice, has information been given on the alternatives?
  - Communicating in an appropriate way. For example, could the information be explained or presented in a way that is easier for the person to understand?
  - Making the person feel at ease. For example, are there particular times of the day when a person's understanding is better?

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<sup>13</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

- Supporting the person. For example, can anyone else help or support the person to understand information and to make a choice?
9. Guidance on how people should be helped to make their own decisions is given in chapter 3 of the Mental Capacity Act (2005) Code of Practice.<sup>14</sup>

### Is the consent given voluntarily?

10. To be valid, consent must be given voluntarily and freely, without pressure or undue influence being exerted on the person either to accept or refuse treatment. Such pressure can come from partners or family members, as well as health or care practitioners. Practitioners should be alert to this possibility and where appropriate should arrange to see the person on their own in order to establish that the decision is truly their own.
11. The test of capacity is set out in the Mental Capacity Act (see paragraph 2 above). Once it has been determined that a person has the capacity to make a particular decision at a particular time, a further requirement (under the common law) for that consent to be valid is that it must be given voluntarily and freely, without pressure or undue influence being exerted upon them.<sup>15</sup>
12. When people are seen and treated in environments where involuntary detention may be an issue, such as prisons and mental hospitals, there is a potential for treatment offers to be perceived coercively, whether or not this is the case. Coercion invalidates consent, and care must be taken to ensure that the person makes decisions freely. Coercion should be distinguished from providing the person with appropriate reassurance concerning their treatment, or pointing out the potential benefits of treatment for the person's health. However, threats such as withdrawal of any privileges, loss of remission of sentence for refusing consent or using such matters to induce consent may well invalidate the consent given, and are not acceptable.

### Has the person received sufficient information?

13. To give valid consent, the person needs to understand the nature and purpose of the procedure. Any misrepresentation of these elements will invalidate consent. Where relevant, information about anaesthesia should be given alongside information about the procedure itself.

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<sup>14</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

<sup>15</sup> That consent needs to be given voluntarily and freely has long been a requirement in the common law; see, for example, *Re T* [1992] and *Freeman v the Home Office* (No 2) [1984]

14. It is particularly important that a person is aware of the situation when students or trainees carry out procedures to further their own education. Where the procedure will further the person's care – for example taking a blood sample for testing – then, assuming the student is appropriately trained in the procedure, the fact that it is carried out by a student does not alter the nature and purpose of the procedure. It is therefore not a legal requirement to tell the person that the clinician is a student, although it would always be good practice to do so. In contrast, where a student proposes to conduct a physical examination that is not part of the person's care then it is essential to explain that the purpose of the examination is to further the student's training, and to seek consent for that to take place.
15. Although informing people of the nature and purpose of procedures enables valid consent to be given as far as any claim of battery is concerned, this is **not** sufficient to fulfil the legal duty of care to the person. Failure to provide other relevant information may render the practitioner liable to an action for negligence if a person subsequently suffers harm as a result of the treatment received.
16. The requirements of the legal duty to inform patients continues to develop in case law. In 1985, the House of Lords decided in the *Sidaway*<sup>16</sup> case that the legal standard to be used when deciding whether adequate information had been given to a patient should be the same as that used when judging whether a doctor had been negligent in their treatment or care of a patient: a doctor would not be considered negligent if their practice conformed to that of a responsible body of medical opinion held by practitioners skilled in the field in question. This is known as the 'Bolam test'.<sup>17</sup> Whether the duty of care had been satisfied was therefore primarily a matter of medical opinion. However, *Sidaway* also stated that it was open to the courts to decide that information about a particular risk was so obviously necessary that it would be negligent not to provide it, even if a 'responsible body' of medical opinion would not have done so.
17. Since *Sidaway*, judgments in a number of negligence cases (relating both to the provision of information and to the standard of treatment given) have shown that courts are willing to be critical of a 'responsible body' of medical opinion. It is now clear that the courts will be the final arbiter of what constitutes responsible practice, although the standards set by the healthcare professions for their members will still be influential. In *Chester v Afshar*, a majority of the House of Lords held that a neurosurgeon who failed to warn a patient of the small risk of injury inherent in surgery, even if properly performed, was liable to the patient when that risk materialised, even though the risk was not increased by the failure to warn and the

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<sup>16</sup> *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871

<sup>17</sup> *Bolam v Friern Hospital Management Committee* [1957] 2 All ER 118

patient had not shown that she would never have had an operation carrying the same risk.<sup>18</sup> The Lords departed from the traditional ‘but for’ test of causation on the basis that, exceptionally, policy and justice required a modification to causation principles. The fundamental principle underlying the decision was the right of a patient to make an informed choice as to whether – and if so, when and by whom – to be operated on.

18. In considering what information to provide, the health practitioner should try to ensure that the person is able to make an informed judgement on whether to give or withhold consent. Case law on this issue is evolving. It is therefore advisable to inform the person of any ‘material’ or ‘significant’ risks or unavoidable risks, even if small, in the proposed treatment; any alternatives to it; and the risks incurred by doing nothing. A Court of Appeal judgment stated that it will normally be the responsibility of the doctor to inform a patient of ‘a significant risk which would affect the judgment of a reasonable patient’.<sup>19</sup> Following *Chester v Afshar*, it is advisable that healthcare professionals give information about all significant possible adverse outcomes and make a record of the information given.
19. The GMC provides guidance on the type of information that patients may need to know before making a decision, and recommends that doctors should do their best to find out about patients’ individual needs and priorities when providing information about treatment options. It advises that discussions should focus on the patient’s ‘individual situation and risk to them’ and sets out the importance of providing the information about the procedure and associated risks in a balanced way and checking that patients have understood the information given.<sup>20</sup> BMA guidance advises that if in doubt about the amount of information to give a patient, doctors ‘should contact their hospital lawyers or their medical defence organisation’.<sup>21</sup>
20. In the very rare event that the healthcare professional believes that to follow the guidance in paragraphs 18 and 19 in full will cause the patient serious harm, the GMC guidance states that this view, and the reasons for it, should be recorded in the patient’s notes. When such concerns arise it is advisable to discuss the issue within the team caring for the patient. In individual cases the courts may accept such a justification but would examine it with great care. The mere fact that the patient might become upset by hearing the information, or might refuse treatment, is **not** sufficient to act as a justification.

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18 *Chester v Afshar* [2004] UKHL 41

19 *Pearce v United Bristol Healthcare NHS Trust* (1999) 48 BMLR 118

20 GMC (2008) *Consent: patients and doctors making decisions together*. London: GMC

21 BMA (2004) *Medical Ethics Today: The BMA’s Handbook of Ethics and Law (second edition)*. Update to chapter 2. London: BMJ Group. [www.bma.org.uk/ethics/MET2007updates.jsp](http://www.bma.org.uk/ethics/MET2007updates.jsp)

21. Some people may wish to know very little about the treatment that is being proposed. If information is offered and declined, it is good practice to record this fact in the notes. However, it is possible that individuals' wishes may change over time, and it is important to provide opportunities for them to express this. GMC and BMA guidance encourages doctors to explain to patients the importance of knowing the options open to them while respecting a person's wish not to know, and states that basic information should always be provided about what the treatment aims to achieve and what it will involve.

### Additional procedures

22. During an operation it may become evident that the person could benefit from an additional procedure that was not within the scope of the original consent. If it would be unreasonable to delay the procedure until the person regains consciousness (for example because there is a threat to the person's life) it may be justified to perform the procedure on the grounds that it is in the person's best interests. However, the procedure should not be performed merely because it is convenient. For example, a hysterectomy should never be performed during an operation without explicit consent, unless it is necessary to do so to save life.
23. If a person has refused certain additional procedures before the anaesthetic (for example, specifying that a mastectomy should not be carried out after a frozen section biopsy result), then this must be respected if the refusal is applicable to the circumstances (see paragraphs 47–52 for more details on advance decisions). The GMC guidance states that it is good practice to seek the views of the patient on possible additional procedures when seeking consent for the original intervention.

### Subsequent use of removed tissue

24. The Human Tissue Act 2004 repeals and replaces the Human Tissue Act 1961, the Anatomy Act 1984 and the Human Organ Transplants Act 1989 as they relate to England and Wales. It also repeals and replaces the Human Tissue Act (Northern Ireland) 1962, the Human Organ Transplants (Northern Ireland) Order 1989 and the Anatomy (Northern Ireland) Order 1992.
25. The 2004 Act makes consent the fundamental principle underpinning the lawful retention and use of body parts, organs and tissue from the living or the deceased for specified health-related purposes and public display. It also covers the **removal** of such material from the deceased. (It does not cover removal of such material from living patients – this continues to be dealt with under the common law and the Mental Capacity Act 2005.)

26. The 2004 Act regulates removal, storage and use of human tissue. This is referred to in the Act as ‘relevant material’ and is defined as material that has come from a human body and consists of, or includes, human cells. Cell lines are excluded, as are hair and nail from living people. Live gametes and embryos are excluded as they are already regulated under the Human Fertilisation and Embryology Act 1990<sup>22</sup> as amended by the Human Fertilisation and Embryology Act 2008.<sup>23</sup>
27. The Human Tissue Act 2004 lists the purposes for which consent is required in Schedule 1, and they are referred to as ‘scheduled purposes’. The consent required under the Act is called ‘appropriate consent’, which means consent from the appropriate person, as identified in the Act. Where there has been a failure to obtain or misuse of consent, penalties of up to three years imprisonment or a fine, or both, are provided for in the Act.
28. Full details on the requirements of the Human Tissue Act 2004 and the HTA’s codes of practice are on the HTA’s website at [www.hta.gov.uk](http://www.hta.gov.uk). These should be consulted to ensure compliance.

### Consent to visual and audio recordings

29. Consent should be obtained for any visual or audio recording, including photographs or other visual images. The purpose and possible future use of the recording must be clearly explained to the person before their consent is sought for the recording to be made. If it is to be used for teaching, audit or research, people must be aware that they can refuse without their care being compromised and that when required or appropriate it can be anonymised. GMC guidance gives more detailed advice, including situations when permission is not required and about obtaining consent to use recordings as part of the assessment or treatment of patients and for training or research.<sup>24</sup>

### Who should seek consent?

30. The clinician providing the treatment or investigation is responsible for ensuring that the person has given valid consent before treatment begins, although the consultant responsible for the person’s care will remain ultimately responsible for the quality of medical care provided. The GMC guidance states that the task of seeking consent may be delegated to another person, as long as they are suitably trained and qualified. In particular, they must have sufficient knowledge of the proposed investigation or treatment, and understand the risks involved, in order to be able to provide any

22 [www.opsi.gov.uk/acts/acts1990/ukpga\\_19900037\\_en\\_1](http://www.opsi.gov.uk/acts/acts1990/ukpga_19900037_en_1)

23 [www.opsi.gov.uk/acts/acts2008/ukpga\\_20080022\\_en\\_1](http://www.opsi.gov.uk/acts/acts2008/ukpga_20080022_en_1)

24 GMC (2002) *Making and Using Visual and Audio Recordings of Patients*. London: GMC  
[www.gmc-uk.org/guidance/current/library/making\\_audiovisual.asp](http://www.gmc-uk.org/guidance/current/library/making_audiovisual.asp)

information the patient may require. The practitioner who eventually carries out the investigation or treatment must also be able to determine whether the person has the capacity to make the decision in question and what steps need to be taken if the person lacks the capacity to make that decision (see chapter 2). Inappropriate delegation (for example where the clinician seeking consent has inadequate knowledge of the procedure) may mean that the ‘consent’ obtained is not valid. Clinicians are responsible for knowing the limits of their own competence, and should seek the advice of appropriate colleagues when necessary.

### When should consent be sought?

31. The seeking and giving of consent is usually a process, rather than a one-off event. For major interventions, it is good practice where possible to seek the person’s consent to the proposed procedure well in advance, when there is time to respond to the person’s questions and provide adequate information (see paragraphs 13–21 above). Clinicians should then check, before the procedure starts, that the person still consents. If a person is not asked to signify their consent until just before the procedure is due to start, at a time when they may be feeling particularly vulnerable, there may be real doubt as to its validity. In no circumstances should a person be given routine pre-operative medication before being asked for their consent to proceed with the treatment.

### Form of consent

32. The validity of consent does not depend on the form in which it is given. Written consent merely serves as evidence of consent: if the elements of voluntariness, appropriate information and capacity have not been satisfied, a signature on a form will not make the consent valid.
33. Although completion of a consent form is in most cases not a legal requirement (exceptions include certain requirements of the Mental Health Act 1983 and of the Human Fertilisation and Embryology Act 1990 as amended by the Human Fertilisation and Embryology Act 2008) the use of such forms is good practice where an intervention such as surgery is to be undertaken. Where there is any doubt about the person’s capacity, it is important, **before** the person is asked to sign the form, to establish both that they have the capacity to consent to the intervention and that they have received enough information to enable valid consent to be given. Details of the assessment of capacity, and the conclusion reached, should be recorded in the case notes.
34. If the person has capacity, but is unable to read or write, they may be able to make their mark on the form to indicate consent. It would be good practice for the mark

to be witnessed by a person other than the clinician seeking consent, and for the fact that the person has chosen to make their mark in this way to be recorded in the case notes. Similarly, if the person has capacity, and wishes to give consent, but is physically unable to mark the form, this fact should be recorded in the notes. Or, the person can direct someone to sign the form on their behalf, but there is no legal requirement for them to do so. If consent has been given validly, the lack of a completed form is no bar to treatment, but a form can be important evidence of such consent.

35. Consent may be expressed verbally or non-verbally: an example of non-verbal consent would be where a person, after receiving appropriate information, holds out an arm for their blood pressure to be taken. However, the person must have understood what examination or treatment is intended, and why, for such consent to be valid. It is good practice to obtain written consent for any significant procedure, such as a surgical operation or when the person participates in a research project or a video recording (even if only minor procedures are involved).

### Requirements concerning gametes

36. It is a legal requirement under the Human Fertilisation and Embryology Act 1990 as amended by the Human Fertilisation and Embryology Act 2008 that consent must be obtained in writing before a person's gametes can be used for the treatment of others, or to create an embryo *in vitro*. Consent in writing is also required for the storage of gametes. Information and an opportunity to receive counselling must be provided before the consent is given. Where these requirements are not satisfied, it is unlawful to store or use the person's gametes for these purposes. Clinicians should ensure that written consent to storage exists before retrieving gametes.
37. Outside specialist infertility practice, these requirements may be relevant to health practitioners whose patients are about to undergo treatment that might render them sterile (such as chemotherapy or radiotherapy), where a patient may wish to have gametes, or ovarian or testicular tissue, stored prior to the procedure. Healthcare practitioners may also receive requests to remove gametes from a person who is unable to give consent.

### Requirements for living donation

38. The HTA is responsible for the regulation, through a system of approvals, of the donation from living people of solid organs, bone marrow and peripheral blood stem cells for transplantation into others. Information on the legal requirements and how to proceed is available from the HTA.<sup>25</sup>

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<sup>25</sup> [www.hta.gov.uk](http://www.hta.gov.uk)

## Research and innovative treatment

39. The same legal principles apply when seeking consent from a person for research purposes as when seeking consent for investigations or treatment. GMC guidance advises that patients 'should be told how the proposed treatment differs from the usual methods, why it is being offered, and if there are any additional risks or uncertainties'. Clinical trials are covered by the Medicines for Human Use (Clinical Trial Regulations) 2004.<sup>26</sup>
40. If the treatment being offered is of an experimental nature, but not actually part of a research trial, this fact must be clearly explained to a person with capacity before their consent is sought, along with information about standard alternatives. It is good practice to give a person information about the evidence to date of the effectiveness of the new treatment, both at national/international levels and in the practitioner's own experience, including information about known possible side-effects.
41. Where the person is an adult who lacks capacity or a child, then the experimental treatment cannot be given, unless it would be in their best interests. In the case of *Simms v Simms*, the court found that where a responsible body of relevant professional opinion supported innovative treatment, that treatment would meet the 'Bolam test' (see paragraph 16).<sup>27</sup> Where there is no alternative treatment available and the disease is progressive and fatal, it will be reasonable to consider experimental treatment with unknown benefits and risks but without significant risks of increased suffering to the patient, and where there is some chance of benefit to the patient. In this case, the court held that the treatment was in the best interests of both a child and an adult lacking capacity.

## Duration of consent

42. When a person gives valid consent to an intervention, in general that consent remains valid for an indefinite duration, unless it is withdrawn by the person. However, if new information becomes available regarding the proposed intervention (for example new evidence of risks or new treatment options) between the time when consent was sought and when the intervention is undertaken, the GMC guidance states that a doctor or member of the healthcare team should inform the patient and reconfirm their consent. In the light of paragraph 19 above, the clinician should consider whether the new information should be drawn to the attention of the patient and the process of seeking consent repeated on the basis of this information. Similarly, if the patient's condition has changed significantly in the intervening time it may

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<sup>26</sup> *Medicines for Human Use (Clinical Trials) Regulations 2004*, SI 1031. [www.legislation.gov.uk/si/si2004/20041031.htm](http://www.legislation.gov.uk/si/si2004/20041031.htm)

<sup>27</sup> *Simms v Simms* [2003] Fam 83

be necessary to seek consent again, on the basis that the likely benefits and/or risks of the intervention may also have changed.

43. If consent has been obtained a significant time before undertaking the intervention, it is good practice to confirm that the person who has given consent (assuming that they retain capacity) still wishes the intervention to proceed, even if no new information needs to be provided or further questions answered. The position of those who lack capacity is covered in chapter 2.

### When consent is refused

44. If an adult with capacity makes a voluntary and appropriately informed decision to refuse treatment (whether contemporaneously or in advance), this decision **must** be respected, except in certain circumstances as defined by the Mental Health Act 1983 (see chapter 5). This is the case even where this may result in the death of the person (and/or the death of an unborn child, whatever the stage of the pregnancy).<sup>28</sup> Refusal of treatment by those under the age of 18 is covered in chapter 3.

### Withdrawal of consent

45. A person with capacity is entitled to withdraw consent at any time, including during the performance of a procedure. Where a person does object during treatment, it is good practice for the practitioner, if at all possible, to stop the procedure, establish the person's concerns and explain the consequences of not completing the procedure. At times, an apparent objection may in fact be a cry of pain rather than withdrawal of consent, and appropriate reassurance may enable the practitioner to continue with the person's consent. If stopping the procedure at that point would genuinely put the life of the person at risk, the practitioner may be entitled to continue until that risk no longer applies.
46. Assessing capacity during a procedure may be difficult and, as noted above, factors such as pain, panic and shock may diminish capacity to consent. The practitioner should try to establish whether at that time the person has capacity to withdraw a previously given consent. If capacity is lacking, it may sometimes be justified to continue in the person's best interests (see chapter 2), but this should not be used as an excuse to ignore distress.

### Advance decisions to refuse treatment

47. A person may have made an advance decision to refuse particular treatment in anticipation of future incapacity (sometimes previously referred to as a 'living will')

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<sup>28</sup> *Re B* [2002] 1 FLR 1090

or ‘advance directive’). A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision to refuse treatment. This is a well-established rule of common law, and the Mental Capacity Act 2005 now puts advance decisions on a statutory basis. The Act sets out the requirements that such a decision must meet to be valid and applicable. Further details are available in chapter 9 of the Mental Capacity Act (2005) Code of Practice, but in summary these are:<sup>29</sup>

- the person must be 18 or over
  - the person must have the capacity to make such a decision
  - the person must make clear which treatments they are refusing
  - if the advance decision refuses life-sustaining treatment, it must be in writing (it can be written by someone else or recorded in healthcare notes), it must be signed and witnessed and it must state clearly that the decision applies even if life is at risk
  - a person with capacity can withdraw their advance decision at any time.
48. Healthcare professionals **must follow** an advance decision if it is valid and applicable, even if it may result in the person’s death. If they do not, they could face criminal prosecution or civil liability. The Mental Capacity Act 2005 protects a health professional from liability for treating or continuing to treat a person in the person’s best interests if they are not satisfied that an advance decision exists which is valid and applicable. The Act also protects healthcare professionals from liability for the consequences of withholding or withdrawing a treatment if at the time they reasonably believe that there is a valid and applicable advance decision. If there is genuine doubt or disagreement about an advance decision’s existence, validity or applicability, the case should be referred to the Court of Protection. The court does not have the power to overturn a valid and applicable advance decision. While a decision is awaited from the courts, healthcare professionals can provide life-sustaining treatment or treatment to stop a serious deterioration in the patient’s condition.
49. If an advance decision is not valid or applicable to current circumstances, healthcare professionals must consider the advance decision as part of their assessment of the person’s best interests (see chapter 2, paragraph 8). Advance decisions made before the Mental Capacity Act came into force may still be valid if they meet the provisions of the Act. There are transitional arrangements for advance decisions to refuse life-sustaining treatment made before 1 October 2007. Further information is available on the Department of Health website.<sup>30</sup>

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<sup>29</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

<sup>30</sup> [www.dh.gov.uk/en/PublicHealth/Scientificdevelopmentgeneticsandbioethics/Consent/DH\\_076863](http://www.dh.gov.uk/en/PublicHealth/Scientificdevelopmentgeneticsandbioethics/Consent/DH_076863)

50. Some healthcare professionals may disagree in principle with a person's right to refuse life-sustaining treatment. The Mental Capacity Act does not change the current legal position. Healthcare professionals do not have to act in a way that goes against their beliefs; however, they must not simply abandon patients or cause their care to suffer. A patient should have the option of transferring their care to another healthcare professional or, if the patient lacks capacity, arrangements should be made for the management of the patient's care to be transferred to another healthcare professional.<sup>31</sup>
51. Patients should always be offered measures that are essential to keeping them comfortable.<sup>32</sup> This is sometimes referred to as 'basic' or 'essential' care, and includes warmth, shelter, actions to keep a person clean and free from distress and the offer of food and water by mouth. The BMA's guidance advises that basic care should always be provided unless it is actively resisted by a patient, and that 'refusals of basic care by patients with capacity should be respected, although it should be continued to be offered'. Advance decisions made under the Mental Capacity Act cannot refuse actions that are needed to keep a person comfortable. The Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity. An advance decision can refuse artificial nutrition and hydration.
52. However, although basic/essential care would include the offer of oral nutrition and hydration, it would **not** cover force feeding an individual or the use of artificial nutrition and hydration. The courts have recognised that an individual with capacity has the right to choose to refuse food and drink, although this may be qualified if the person has a mental disorder. Towards the end of such a period an individual is likely to lose capacity, and the courts have stated that if the individual has, while they have capacity, expressed the desire to refuse food until death supervenes, the person cannot be force fed or fed artificially when they lack capacity. If the person is refusing food as a result of mental disorder, then detention and treatment without consent may be a possibility under the Mental Health Act 1983, different considerations may apply and more specialist guidance should be consulted.<sup>33</sup>

## Self-harm

53. Cases of self-harm present a particular difficulty for healthcare professionals. Where the person is able to communicate, an assessment of their mental capacity should be made as a matter of urgency. If the person is judged not to have capacity, then they

31 *Re B (adult: refusal of medical treatment)* [2002] EWHC 429 (Fam) at paragraph 100(viii); paragraph 9.61 of the Mental Capacity Act (2005) Code of Practice

32 BMA (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making (third edition)* (Part 2.11). London: BMJ Group

33 Mental Health Act Commission (1979) *Guidance Note 3: Guidance on the treatment of anorexia nervosa under the Mental Health Act 1983* (updated March 1999)

may be treated on the basis of temporary incapacity (see chapter 2, paragraph 12). Similarly, patients who have attempted suicide and are unconscious should be given emergency treatment if any doubt exists as to either their intentions or their capacity when they took the decision to attempt suicide.

54. However, as noted in paragraph 47 above, patients with capacity **do** have the right to refuse life-sustaining treatment (other than treatment for mental disorder under the Mental Health Act 1983) – both at the time it is offered and in the future. Making a decision which, if followed, may result in death does not necessarily mean that a person is or feels suicidal. Nor does it necessarily mean that the person lacks the capacity to make the decision now or in advance. If the person is clearly suicidal, this may raise questions about their capacity to make the decision. If a patient with capacity has harmed themselves, a prompt psychosocial assessment of their needs should be offered. However, if the person refuses treatment and use of the Mental Health Act 1983 is not appropriate, then their refusal must be respected.<sup>34</sup> Similarly, if practitioners have good reason to believe that a patient genuinely intended to end their life and had capacity when they took that decision, and are satisfied that the Mental Health Act is not applicable, then treatment should not be forced upon the person, although clearly attempts should of course be made to encourage them to accept help.

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34 National Collaborating Centre for Mental Health, commissioned by the National Institute for Clinical Excellence (2004) National Clinical Practice Guideline 16: *Self-harm*. [www.nice.org.uk/nicemedia/pdf/CG16FullGuideline.pdf](http://www.nice.org.uk/nicemedia/pdf/CG16FullGuideline.pdf)

# 2 Adults without capacity

## General principles

1. The Mental Capacity Act 2005 came fully into force in October 2007 and applies in England and Wales to everyone who works in health and social care and is involved in the care, treatment or support of people over 16 years of age who may lack capacity to make decisions for themselves. It is largely based on previous common law and creates a single, coherent framework for decision-making, including decisions about treatment. This chapter summarises the main provisions of the Mental Capacity Act. Detailed guidance is provided in the Code of Practice,<sup>35</sup> which has statutory force. The Act imposes a duty on health professionals (and other healthcare staff) to have regard to the Code of Practice.
2. Under English law, no one is able to give consent to the examination or treatment of an adult who lacks the capacity to give consent for themselves, unless they have been authorised to do so under a Lasting Power of Attorney or they have the authority to make treatment decisions as a court appointed deputy (see paragraphs 14–20). Therefore, in most cases, parents, relatives or members of the healthcare team cannot consent on behalf of such an adult. However, the Mental Capacity Act sets out the circumstances in which it will be lawful to carry out such examinations or treatment.
3. In general, the refusal to an intervention made by a person when they had capacity cannot be overridden if the advance decision is valid and applicable to the situation (see chapter 1, paragraph 47). There are certain statutory exceptions to this principle, including treatment for mental disorder under the Mental Health Act 1983, which are set out briefly in chapter 5.
4. The legal requirements in the Mental Capacity Act are underpinned by five statutory principles. One of these key principles is that any act done for, or any decision made on behalf of, a person who lacks capacity must be done, or made, in that person's best interests. This principle applies to health professionals as it does to anyone working with and caring for a person who lacks capacity. The Act also creates a new offence of ill treatment or wilful neglect of someone who lacks capacity by someone with responsibility for their care or with decision-making powers.

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<sup>35</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

5. Information on assessing capacity is given in chapter 1, paragraph 2, and in this guidance a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.
6. The Mental Capacity Act provides healthcare professionals with protection from civil and criminal legal liability for acts or decisions made in the best interests of the person who lacks capacity. The Act makes it clear that when determining what is in a person's best interests a healthcare professional must not make assumptions about someone's best interests merely on the basis of the person's age or appearance, condition or any aspect of their behaviour.
7. The Act requires that a healthcare professional **must** consider all the relevant circumstances relating to the decision in question. These are described as factors that the healthcare professional is aware of and which are reasonable to take into account.
8. In considering the relevant circumstances, the Act rules that the healthcare professionals **must** take the following steps:
  - Consider whether the person is likely to regain capacity and if so whether the decision can wait.
  - Involve the person as fully as possible in the decision that is being made on their behalf.
  - As far as possible, consider:
    - the person's past and present wishes and feelings (in particular if they have been written down)
    - any beliefs and values (eg religious, cultural or moral) that would be likely to influence the decision in question, and any other relevant factors, and
    - the other factors that the person would be likely to consider if they were able to do so.
  - As far as possible, consult other people if it is appropriate to do so and take into account their views as to what would be in the best interests of the person lacking capacity, especially:
    - anyone previously named by the person lacking capacity as someone to be consulted
    - anyone engaging in caring for or interested in the person's welfare
    - any attorney appointed under a Lasting Power of Attorney (see paragraphs 14–16)
    - any deputy appointed by the Court of Protection to make decisions for the person (see paragraphs 17–20).

- For decisions about serious medical treatment, where there is no one appropriate other than paid staff, healthcare professionals have to instruct an IMCA (see paragraphs 21–23).
  - If the decision concerns the provision or withdrawal of life-sustaining treatment, the person making the best interests decision must not be motivated by a desire to bring about the person’s death.
9. The Mental Capacity Act (2005) Code of Practice makes it clear that the steps set out in the Act should form the starting point for considering all the relevant circumstances of each case, and often other factors will be important. Further guidance on interpreting best interests is provided in chapter 5 of the Code of Practice.<sup>36</sup>
  10. Healthcare professionals should demonstrate in their record-keeping that the decision has been based on all available evidence and has taken into account any conflicting views. What is in a person’s best interests may well change over time. This means that even where similar actions need to be taken repeatedly in connection with the person’s care or treatment, the person’s best interests should be reviewed regularly.
  11. In cases of serious doubt or dispute about an individual’s mental capacity or best interests, an application can be made to the Court of Protection for a ruling. The duty officer of the Official Solicitor can advise on the appropriate procedure if necessary.<sup>37</sup> See also chapter 8 of the Mental Capacity Act (2005) Code of Practice for further information.<sup>38</sup> Details of the circumstances in which a referral should be made to the court are given in paragraph 26.

### Duration of lack of capacity

12. The provisions of the Mental Capacity Act apply to acts or decisions made on behalf of an adult who lacks capacity – whether the lack of capacity is likely to be temporary or permanent. It is possible for capacity to fluctuate. In such cases, it is good practice to establish, while the person has capacity, their views about any clinical intervention that may be necessary during a period of anticipated incapacity, and to record these views. The person may wish to make an advance decision to refuse treatment (see chapter 1, paragraph 47) or a statement of their preferences and wishes (see paragraph 13). If the person does not make a relevant advance decision, decisions about that person’s treatment if they lack capacity must be made in accordance with the Mental

<sup>36</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

<sup>37</sup> Further details about the Official Solicitor can be found at [www.officialsolicitor.gov.uk/os/offsol.htm](http://www.officialsolicitor.gov.uk/os/offsol.htm) (contact would usually be made through the legal department of the NHS body involved)

<sup>38</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

Capacity Act (see paragraph 2 above). This would include considering whether the person is likely to regain capacity and, if so, whether the decision can wait, as well as the statutory principle that all practical steps must be taken to enable the person to make their own decision.

## Statements of preferences and wishes

13. A healthcare professional must take all statements of a person's preferences and wishes into consideration as part of a best interests assessment. Written statements which request specific treatments made by a person before losing capacity should be given the same consideration as those made by people who currently have capacity to make treatment decisions. However, a healthcare professional would not have to follow a written request if they thought that the specific treatment would be clinically unnecessary or not appropriate for the person's condition, and therefore not in the person's best interests. If the decision is different to a written statement, a healthcare professional should keep a record of this and be prepared to justify the decision if challenged. There is an important legal distinction between a written statement expressing treatment preferences, which a healthcare professional must take into account when making a best interests decision, and a valid and applicable advance decision to refuse treatment (see chapter 1, paragraph 47), which healthcare professionals must follow. Healthcare professionals cannot ignore a written statement that is a valid and applicable advance decision to refuse treatment.

## Lasting Power of Attorney

14. The Mental Capacity Act enables a person aged 18 or over to appoint an attorney to look after their health and welfare decisions if they should lack the capacity to make such decisions in the future. Under a personal welfare LPA, the attorney – if they have the authority to do so – can make decisions that are as valid as those made by the person themselves. The LPA must be made in the form, and meet the criteria, set out in the regulations,<sup>39</sup> and it must be registered with the Office of the Public Guardian before it can be used.
15. The LPA may specify limits to the attorney's authority, and the LPA must specify whether or not the attorney has the authority to make decisions about life-sustaining treatment. Healthcare practitioners directly involved in the care or treatment of a person who lacks capacity should not agree to act as that person's attorney other than in exceptional circumstances (for example if they are the only close relative of the person). If the person lacks capacity and has created a personal welfare LPA, the

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<sup>39</sup> *Mental Capacity Act 2005 (Lasting Powers of Attorney, Enduring Powers of Attorney and Public Guardian) Regulations 2007*, SI 2007, 2161 and [www.publicguardian.gov.uk/forms/Making-an-LPA.htm](http://www.publicguardian.gov.uk/forms/Making-an-LPA.htm)

attorney will have the authority to make decisions and consent to or refuse treatment as set out in the LPA. Healthcare practitioners should read the LPA if it is available, in order to understand the extent of the attorney's power.

16. The attorney must follow the statutory principles under the Mental Capacity Act and make decisions in the best interests of the person lacking capacity. If the decision is about life-sustaining treatment, the attorney must not be motivated by a desire to bring about the person's death. Attorneys also have a legal duty to have regard to the guidance in the Mental Capacity Act (2005) Code of Practice. If there is a dispute that cannot be resolved, eg between the attorney and a doctor, it may have to be referred to the Court of Protection. More information about LPAs is given in chapter 7 of the Code of Practice.<sup>40</sup>

### Court appointed deputies

17. If a person lacks capacity to make a decision relating to their personal welfare, then the Court of Protection can make an order making a decision on their behalf. Alternatively, the Court of Protection can appoint a deputy to make decisions on behalf of the person who lacks capacity. The Mental Capacity Act makes it clear that in such situations it is preferable for the Court of Protection to make the decision if at all possible, and that if a deputy is appointed, then their powers should be limited in scope to what is absolutely necessary.
18. The court must ensure that any deputy appointed has the necessary skills and abilities and is prepared to take on the duty and responsibility of the role. Both the court and any deputy must follow the statutory principles of the Act and make decisions in the person's best interests.
19. Deputies for personal welfare decisions will only be required in the most difficult cases, where important and necessary actions cannot be carried out without the court's authority or where there is no other way of settling the matter in the best interests of the person who lacks capacity. For example, a deputy could be appointed to make ongoing decisions, having consulted all relevant parties. This could be useful where there is a history of family disputes.
20. If a deputy has been appointed to make treatment decisions on behalf of a person who lacks capacity then it is the deputy rather than the healthcare professional who makes the treatment decision. A deputy cannot go against a decision of an attorney under an LPA made before the person lacks capacity. Deputies must follow the Mental Capacity Act's statutory principles and must make decisions in the person's best interests. A deputy cannot refuse consent to the provision of life-sustaining

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<sup>40</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

treatment. More information about the powers of the Court of Protection and the role of deputies is given in chapter 8 of the Code of Practice.<sup>41</sup>

## Independent mental capacity advocates

21. The Mental Capacity Act has, since April 2007 in England and since October 2007 in Wales, introduced a duty on NHS bodies to instruct an IMCA in serious medical treatment decisions when a person who lacks capacity to make a decision has no one who can speak for them, other than paid staff. In matters that meet the definition of serious medical treatment,<sup>42</sup> IMCAs are only able to represent and support people whose treatment is arranged by the NHS. They have the right to information about an individual and can see relevant healthcare records.
22. The duties of an IMCA are to:
  - support the person who lacks capacity and represent their views and interests to the decision-maker
  - obtain and evaluate information, both through interviewing the person and through examining relevant records and documents
  - obtain the views of professionals providing treatment for the person who lacks capacity
  - identify alternative courses of action
  - obtain a further medical opinion, if required, and
  - prepare a report (that the decision-maker must consider).
23. IMCAs are not decision-makers for the person who lacks capacity. They are there to support and represent that person and to ensure that decision-making for people who lack capacity is done appropriately and in accordance with the Mental Capacity Act. More information is given at [www.dh.gov.uk/imca](http://www.dh.gov.uk/imca) and in chapter 10 of the Mental Capacity Act (2005) Code of Practice.<sup>43</sup>

## Consent forms

24. Where treatment is provided to a person who lacks capacity following a best interests decision, any consent form should not be signed by someone else unless they have a personal welfare LPA that authorises them to make the decision in question, or

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41 [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

42 See Mental Capacity Act (2005) Code of Practice, chapter 10, paragraph 10.42 et seq. for further information on what is regarded as 'serious medical treatment'. [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

43 [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

they are a court appointed deputy with similar authority. It is good practice to note either in the records or on a 'patient unable to consent' form why the treatment was decided to be in the patient's best interests.

## Referral to court

25. The Mental Capacity Act established the Court of Protection to deal with decision-making for adults (and children in a few cases) who may lack the capacity to make specific decisions for themselves. The Court of Protection deals with serious decisions affecting personal welfare matters, including healthcare, which were previously dealt with by the High Court. In cases of serious dispute, where there is no other way of finding a solution or when the authority of the court is needed in order to make a particular decision or take a particular action, the court can be asked to make a decision.
26. The courts have identified certain circumstances when referral should be made to them for a ruling on lawfulness before a procedure is undertaken. These are:
  - decisions about the proposed withholding or withdrawal of ANH from patients in a permanent vegetative state
  - cases involving organ, bone marrow or peripheral blood stem cell donation by an adult who lacks the capacity to consent (see chapter 3 for information on children)
  - cases involving the proposed non-therapeutic sterilisation of a person who lacks the capacity to consent to this (eg for contraceptive purposes), and
  - all other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.
27. Other cases likely to be referred to the court include those involving ethical dilemmas in untested areas (such as innovative treatments for variant CJD<sup>44</sup>), or where there are otherwise irresolvable conflicts between healthcare staff, or between staff and family members. More information about the powers of the Court of Protection and the cases that should be referred to the court is given in the Mental Capacity Act (2005) Code of Practice and in a Court of Protection Practice Direction.<sup>45</sup>
28. The courts have stated that neither sterilisation which is incidental to the management of the detrimental effects of menstruation nor abortion need automatically be referred to court if there is no doubt that this is the most appropriate

44 *Simms v An NHS Trust* [2002] EWHC 2734 (Fam)

45 [www.publicguardian.gov.uk/docs/09E\\_-\\_Serious\\_Medical\\_Treatment\\_PD.pdf](http://www.publicguardian.gov.uk/docs/09E_-_Serious_Medical_Treatment_PD.pdf)

therapeutic response. However, these procedures can give rise to special concern about the best interests and rights of a person who lacks capacity. The need for such procedures occasionally arises in relation to women with a severe learning disability. It is good practice to involve as part of the decision-making process a consultant in the psychiatry of learning disability, the multidisciplinary team and the patient's family, and to document their involvement. Less invasive or reversible options should always be considered before permanent sterilisation. Where there is disagreement as to the patient's best interests, a reference to court may be appropriate.

29. It should be noted that, in the future, the courts may extend the list of procedures concerning which referral to the court is good practice.
30. Although some procedures may not require court approval, their appropriateness may give rise to concern. For example, some patients with learning disability may exhibit challenging behaviour, such as biting or self-injury. If such behaviour is severe, interventions such as applying a temporary soft splint to the teeth or using arm splints to prevent self-injury are exceptionally considered, within a wider therapeutic context. As with hysterectomies undertaken for menstrual management purposes, great care must be taken in determining the best interests of such patients as distinct from dealing with the needs of carers and others who are concerned with the individual's treatment.

## Research

31. The Mental Capacity Act sets out a legal framework for involving people who lack the capacity to consent to taking part in research. The Act provides for when such research can be carried out and for safeguards to protect people involved in the research who lack capacity, for example ensuring that the wishes and feelings of the person who lacks capacity are respected. Anyone setting up or carrying out such research will need to make sure that the research complies with the provisions set out in the Act and will need to follow the guidance given in chapter 11 of the Mental Capacity Act (2005) Code of Practice.<sup>46</sup> The Act does not include clinical trials, which are covered by the Medicines for Human Use (Clinical Trial Regulations) 2004.
32. The Act requires that a family member or unpaid carer must be consulted about any proposal and agree that the person who lacks capacity can be part of the research. If such a person cannot be identified, then the researcher must nominate a person who is independent of the research project to provide advice on the participation of the person who lacks capacity in the research. The person consulted should be asked for advice about whether the person who lacks capacity should participate in the research project and what, in their opinion, the person's wishes and feelings about taking

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<sup>46</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

part would be likely to be if they had capacity. The person's past or present wishes, feelings and values are most important in deciding whether they should take part in research or not. If the person without capacity shows any sign that they are not happy to be involved in the research, then the research will not be allowed to continue.

33. Healthcare professionals may be providing care or treatment for a person who is taking part in a research project, and may be asked for their views about what the person's feelings are or need to advise the researchers if the person seems upset about any aspect of the research.

## 3 Children and young people

1. The legal position concerning consent and refusal of treatment by those under the age of 18 is different from the position for adults. For the purposes of this guidance ‘children’ refers to people aged below 16 and ‘young people’ refers to people aged 16–17.

### Young people aged 16–17

2. By virtue of section 8 of the Family Law Reform Act 1969,<sup>47</sup> people aged 16 or 17 are presumed to be capable of consenting to their own medical treatment, and any ancillary procedures involved in that treatment, such as an anaesthetic. As for adults, consent will be valid only if it is given voluntarily by an appropriately informed young person capable of consenting to the particular intervention. However, unlike adults, the refusal of a competent person aged 16–17 may in certain circumstances be overridden by either a person with parental responsibility or a court (see paragraphs 14–18 below).
3. Section 8 of the Family Law Reform Act 1969 applies only to the young person’s own treatment. It does not apply to an intervention that is not potentially of direct health benefit to the young person, such as blood donation or non-therapeutic research on the causes of a disorder. However, a young person may be able to consent to such an intervention under the standard of Gillick competence, considered below (see paragraph 6 et seq.).
4. In order to establish whether a young person aged 16 or 17 has the requisite capacity to consent to the proposed intervention, the same criteria as for adults should be used (see chapter 1, paragraph 2). If a young person lacks capacity to consent because of an impairment of, or a disturbance in the functioning of, the mind or brain then the Mental Capacity Act 2005 will apply in the same way as it does to those who are 18 and over (see chapter 2). If however they are unable to make the decision for some other reason, for example because they are overwhelmed by the implications of the decision, then the Act will not apply to them and the legality of any treatment should be assessed under common law principles. It may be unclear whether a young person lacks capacity within the meaning of the Act. In those circumstances, it would be prudent to seek a declaration from the court. More information on how the Act applies

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47 [www.opsi.gov.uk/RevisedStatutes/Acts/ukpga/1969/cukpga\\_19690046\\_en\\_2#ptH1g8](http://www.opsi.gov.uk/RevisedStatutes/Acts/ukpga/1969/cukpga_19690046_en_2#ptH1g8)

to young people is given in chapter 12 of the Mental Capacity Act (2005) Code of Practice.<sup>48</sup>

5. If the 16/17-year-old is capable of giving valid consent then it is not legally necessary to obtain consent from a person with parental responsibility for the young person in addition to the consent of the young person. It is, however, good practice to involve the young person's family in the decision-making process – unless the young person specifically wishes to exclude them – if the young person consents to their information being shared.

### Children under 16 – the concept of Gillick competence

6. In the case of *Gillick*, the court held that children who have sufficient understanding and intelligence to enable them to understand fully what is involved in a proposed intervention will also have the capacity to consent to that intervention.<sup>49</sup> This is sometimes described as being 'Gillick competent'. A child of under 16 may be Gillick competent to consent to medical treatment, research, donation or any other activity that requires their consent.
7. The concept of Gillick competence is said to reflect a child's increasing development to maturity. The understanding required for different interventions will vary considerably. Thus a child under 16 may have the capacity to consent to some interventions but not to others. The child's capacity to consent should be assessed carefully in relation to each decision that needs to be made.
8. In some cases, for example because of a mental disorder, a child's mental state may fluctuate significantly, so that on some occasions the child appears Gillick competent in respect of a particular decision and on other occasions does not. In cases such as these, careful consideration should be given as to whether the child is truly Gillick competent at the time that they need to take a relevant decision.
9. If the child is Gillick competent and is able to give voluntary consent after receiving appropriate information, that consent will be valid and additional consent by a person with parental responsibility will not be required. It is, however, good practice to involve the child's family in the decision-making process, if the child consents to their information being shared.
10. Where advice or treatment relates to contraception, or the child's sexual or reproductive health, the healthcare professional should try to persuade the child to inform his or her parent(s), or allow the medical professional to do so. If however the child cannot be

<sup>48</sup> [www.publicguardian.gov.uk/mca/code-of-practice.htm](http://www.publicguardian.gov.uk/mca/code-of-practice.htm)

<sup>49</sup> *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112

persuaded, advice and/or treatment should still be given if the healthcare professional considers that the child is very likely to begin or continue to have sexual intercourse with or without advice or treatment, and that unless they receive the advice or treatment then the child's physical or mental health is likely to suffer.

11. If the child seeks advice or treatment in relation to abortion and cannot be persuaded to inform her parent(s), every effort should be made to help the child find another adult (such as another family member or a specialist youth worker) to provide support to the child.<sup>50</sup>

### The requirement of voluntariness

12. Although a child or young person may have the capacity to give consent, this is only valid if it is given voluntarily. This requirement must be considered carefully. Children and young people may be subject to undue influence by their parent(s), other carers or a sexual partner (current or potential), and it is important to establish that the decision is that of the individual him or herself.

### Child or young person with capacity refusing treatment

13. Where a young person of 16 or 17 who could consent to treatment in accordance with section 8 of the Family Law Reform Act 1969, or a child under 16 but Gillick competent, refuses treatment, it is possible that such a refusal could be overruled if it would in all probability lead to the death of the child/young person or to severe permanent injury.
14. In the case of *Re W (a minor) (medical treatment)*,<sup>51</sup> the court stated that it has jurisdiction to override a refusal of a child/young person, at least where they seek to refuse treatment in circumstances that will, in all probability, lead to the death of the child/young person or to severe permanent injury; or where there is a serious and imminent risk that the child/young person will suffer grave and irreversible mental or physical harm.
15. The courts have, in the past, also found that parents can consent to their competent child being treated even where the child/young person is refusing treatment.<sup>52</sup> However, there is no post-Human Rights Act 1998 authority for this proposition, and it would therefore be prudent to obtain a court declaration or decision if faced with a competent child or young person who is refusing to consent to treatment, to determine whether it is lawful to treat the child.

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<sup>50</sup> *Axon v Secretary of State for Health* [2006] EWHC 37 (Admin)

<sup>51</sup> *Re W (a minor) (medical treatment)* [1992] 4 All ER 627

<sup>52</sup> *Re R (a minor) (wardship: medical treatment)* [1991] 4 All ER 177

16. Where the treatment involved is for mental disorder, consideration should be given to using mental health legislation.
17. The changes made to section 131 of the Mental Health Act 1983 by section 43 of the Mental Health Act 2007 mean that when a young person of 16 or 17 has capacity (as defined in the Mental Capacity Act 2005) and does not consent to admission for treatment for mental disorder (either because they are overwhelmed, do not want to consent or refuse to consent), they cannot then be admitted informally on the basis of the consent of a person with parental responsibility (see chapter 36 of the Code of Practice to the Mental Health Act 1983, as amended 2008<sup>53</sup>).
18. A life-threatening emergency may arise when consultation with either a person with parental responsibility or the court is impossible, or the person with parental responsibility refuses consent despite such emergency treatment appearing to be in the best interests of the child. In such cases the courts have stated that doubt should be resolved in favour of the preservation of life, and it will be acceptable to undertake treatment to preserve life or prevent serious damage to health.

### Child lacking capacity

19. Where a child under the age of 16 lacks capacity to consent (ie is not Gillick competent), consent can be given on their behalf by any one person with parental responsibility (if the matter is within the 'zone of parental control'<sup>54</sup>) or by the court. As is the case where patients are giving consent for themselves, those giving consent on behalf of child patients must have the capacity to consent to the intervention in question, be acting voluntarily and be appropriately informed. The power to consent must be exercised according to the 'welfare principle': that the child's 'welfare' or 'best interests' must be paramount. Even where a child lacks capacity to consent on their own behalf, it is good practice to involve the child as much as possible in the decision-making process.
20. Where necessary, the courts can overrule a refusal by a person with parental responsibility. It is recommended that certain important decisions, such as sterilisation for contraceptive purposes, should be referred to the courts for guidance, even if those with parental responsibility consent to the operation going ahead.

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53 [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_084597](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084597)

54 The concept of the 'zone of parental control' derives largely from case law from the European Court of Human Rights in Strasbourg. Chapter 36 of the Code of Practice to the Mental Health Act 1983, as amended, gives guidelines about what may fall in the zone, which will depend on the particular facts of each case

21. The European Court of Human Rights judgment in a case where doctors treated a child contrary to his mother's wishes, without a court order (*Glass v United Kingdom*<sup>55</sup>), made clear that the failure to refer such cases to the court is not only a breach of professional guidance but also potentially a breach of the European Convention on Human Rights. In situations where there is continuing disagreement or conflict between those with parental responsibility and doctors, and where the child is not competent to provide consent, the court should be involved to clarify whether a proposed treatment, or withholding of treatment, is in the child's best interests. Parental refusal can only be overridden in an emergency.
22. The Children Act 1989 sets out persons who may have parental responsibility. These include:
  - the child's mother
  - the child's father, if he was married to the mother at the time of birth
  - unmarried fathers, who can acquire parental responsibility in several different ways:
    - For children born before 1 December 2003, unmarried fathers will have parental responsibility if they:
      - marry the mother of their child or obtain a parental responsibility order from the court
      - register a parental responsibility agreement with the court or by an application to court
    - For children born after 1 December 2003, unmarried fathers will have parental responsibility if they:
      - register the child's birth jointly with the mother at the time of birth<sup>56</sup>
      - re-register the birth if they are the natural father
      - marry the mother of their child or obtain a parental responsibility order from the court
      - register with the court for parental responsibility
  - the child's legally appointed guardian<sup>57</sup>
  - a person in whose favour the court has made a residence order concerning the child
  - a local authority designated in a care order in respect of the child

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<sup>55</sup> *Glass v The United Kingdom* – 61827-00 [2004] ECHR 103

<sup>56</sup> Under section 111 of the Adoption and Children Act 2002, unmarried fathers who register their child's birth jointly with the mother will automatically acquire parental responsibility

<sup>57</sup> Under section 5 of the Children Act 1989, courts may appoint a guardian for a child who has no parent with parental responsibility. Parents with parental responsibility may also appoint a guardian in the event of their own death

- a local authority or other authorised person who holds an emergency protection order in respect of the child. Section 2(9) of the Children Act 1989 states that a person who has parental responsibility for a child ‘may arrange for some or all of it to be met by one or more persons acting on his or her behalf’. Such a person might choose to do this, for example, if a childminder or the staff of a boarding school have regular care of their child. As only a person exercising parental responsibility can give valid consent, in the event of any doubt then specific enquiry should be made. Foster parents do not automatically have parental responsibility.
23. Consent given by one person with parental responsibility is valid, even if another person with parental responsibility withholds consent. However, the courts have stated that a ‘small group of important decisions’ should not be taken by one person with parental responsibility against the wishes of another, citing in particular non-therapeutic male circumcision and immunisation.<sup>58</sup> Where persons with parental responsibility disagree as to whether these procedures are in the child’s best interests, it is advisable to refer the decision to the courts. It is possible that major experimental treatment, where opinion is divided as to the benefits it may bring the child, might also fall into this category of important decisions, although such a case has not yet been considered in the English courts.
  24. Where there is doubt about whether a parent is acting in the interest of the child or young person, then the healthcare practitioner would be unwise to rely on the parent’s consent, for example if a child alleges abuse and the parent supports psychiatric treatment for the child. The Government’s guidance *Working Together to Safeguard Children* covers situations involving parental consent where abuse or neglect is suspected.<sup>59</sup>
  25. In order to consent on behalf of a child, the person with parental responsibility must themselves have capacity. Where the person with parental responsibility for a child is themselves under 18, they will only be able to give valid consent for the child’s treatment if they themselves are Gillick competent (see paragraphs 6–11 above). Whether or not they have capacity may vary, depending on the seriousness of the decision to be taken.

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58 Female circumcision is always prohibited, under the Prohibition of Female Circumcision Act 1985; *Re J* [2000] 1 FLR 571 at 577; *Re B (a child) sub nom in Re vaccination/MMR litigation: A v B : D v E sub nom in Re C (a child) (immunisation: parental rights) : in Re F (a child) (immunisation: parental rights)* (2003)

59 HM Government (2006) *Working Together to Safeguard Children: A guide to inter-agency working to safeguard and promote the welfare of children*. London: HM Government. [www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH\\_4007781](http://www.dh.gov.uk/en/PublicationsandStatistics/Publications/PublicationsPolicyAndGuidance/DH_4007781)

26. Where a child is a ward of court, no important step may be taken in the life of the child without the prior consent of the court. This is likely to include more significant medical interventions but not treatment for minor injuries or common diseases of childhood.
27. In an emergency, it is justifiable to treat a child who lacks capacity without the consent of a person with parental responsibility, if it is impossible to obtain consent in time and if the treatment is vital to the survival or health of the child.

## Research

28. Where children lack capacity to consent for themselves, parents may give consent for their child to be entered into a trial where the evidence is that the trial therapy may be at least as beneficial to the patient as the standard therapy. It may also be compatible with the welfare principle for a person with parental responsibility to give consent to a research intervention that is not strictly in the best interests of the child, but is not against the interests of the child either. Such an intervention must involve only minimal burden to the child.
29. Decisions about experimental treatment must be made in the child's best interests (see chapter 1, paragraph 40).

## Using children as bone marrow donors

30. This is covered by the Human Tissue Authority's code of practice on donation of allogeneic bone marrow and peripheral blood stem cells for transplantation, and healthcare professionals should consult this for detailed information on the legal requirements and how to proceed.<sup>60</sup>

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<sup>60</sup> Human Tissue Authority (2006) *Code of Practice – Donation of allogeneic bone marrow and peripheral blood stem cells for transplantation*. Code 6. London: Human Tissue Authority. [www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice.cfm](http://www.hta.gov.uk/legislationpoliciesandcodesofpractice/codesofpractice.cfm)

# 4 Withdrawing and withholding life-sustaining treatment

## General principles

1. A healthcare professional's legal duty is to care for a patient and to take reasonable steps to prolong their life. Although there is a strong presumption in favour of providing life-sustaining treatment, there are circumstances when continuing or providing life-sustaining treatment stops providing a benefit to a patient and is not clinically indicated. There is no legal distinction between withdrawing and withholding life-sustaining treatment. A person with capacity may decide either contemporaneously or by a valid and applicable advance decision that they have reached a stage where they no longer wish treatment to continue. If a person lacks capacity, this decision must be taken in their best interests and in a way that reflects their wishes (if these are known).
2. The legal principles around consent are the same for all medical interventions, including decisions to withdraw or withhold life-sustaining treatment, but the issues surrounding seriously ill or dying patients are necessarily more grave and sensitive. Persons with the capacity to do so can make such decisions for themselves. If the person is an adult who lacks capacity to make such decisions then the provisions of the Mental Capacity Act 2005 will apply to these, as to other decisions. When making a best-interests decision in relation to life-sustaining treatment, healthcare professionals should be aware that the Mental Capacity Act requires that the healthcare professional must not be motivated by a desire to bring about the person's death.
3. Sometimes decisions will need to be made immediately – for example whether it is appropriate to attempt resuscitation after severe trauma.<sup>61</sup> In an emergency situation, where there is doubt as to the appropriateness of treatment, there should be a presumption in favour of providing life-sustaining treatment. When more time is available and the patient is an adult or child without capacity, all those concerned with the care of the patient – relatives, partners, friends, carers and the multidisciplinary team – can potentially make a contribution to the assessment. The discussions and the basis for decisions should be recorded in the notes.
4. Legally, the use of artificial nutrition and hydration (ANH) constitutes medical treatment. Thus the legal principles that apply to the use of ANH are the same

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<sup>61</sup> See circular *Health Service Circular 2000/28* for further guidance on resuscitation decisions. It advises that NHS trusts should have appropriate resuscitation policies in place. [www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH\\_4004244](http://www.dh.gov.uk/en/Publicationsandstatistics/Lettersandcirculars/Healthservicecirculars/DH_4004244)

as those that apply to all other medical treatments, such as medication or ventilation. Decisions about the proposed withholding or withdrawal of ANH from a patient in a permanent vegetative state should be referred to court (see chapter 2, paragraph 26). The courts have confirmed that the current case law in this area is compatible with the Human Rights Act 1998.<sup>62</sup>

5. There is an important distinction between withdrawing or withholding treatment that is of no clinical benefit to the patient or is not in the patient's best interests, and taking a deliberate action to end the patient's life. A deliberate action that is intended to cause death is unlawful. Although there is a strong presumption in favour of providing life-sustaining treatment, there are circumstances when continuing or providing life-sustaining treatment stops providing a benefit to a patient and is not clinically indicated. Healthcare professionals should discuss the situation with a patient with capacity and agree if and when the patient no longer wishes treatment to continue. If the patient lacks capacity, this decision must be taken in their best interests and in a way that reflects their wishes, beliefs and values (if these are known). Suitable care should be provided to ensure that both the comfort and dignity of the patient are maintained.

## Adults and children with capacity

6. Except in circumstances governed by the Mental Health Act 1983, if an adult with the capacity to make the decision refuses life-sustaining treatment, or requests that it be withdrawn, practitioners **must** comply with the person's decision, even if it may result in the person's death. If a refusal is ignored, they will be treating the person unlawfully.<sup>63</sup>
7. The case of *Burke v GMC* established that an adult patient with capacity does not have the legal right to demand treatment that is not clinically indicated. Where a patient with capacity indicates his or her wish to be kept alive by the provision of ANH, the doctor's duty of care will require them to provide ANH while such treatment continues to prolong life. A patient cannot demand that a healthcare professional do something unlawful such as assisting them to commit suicide.
8. If a child with capacity makes such a request or refusal it is possible that such a refusal could be overruled if it would in all probability lead to the death of the child or to severe permanent injury (see chapter 3, paragraph 13). Moreover, the courts consider that to take a decision which may result in the individual's death requires a very high level of understanding, so that many young people who would have the capacity to

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<sup>62</sup> *NHS Trust A v M, NHS Trust B v H* [2002] Fam 348 Fam Div

<sup>63</sup> *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449

take other decisions about their medical care would lack the capacity to make such a grave decision.

9. Refusal of treatment by a child with capacity must always be taken very seriously, even though legally it is possible to override their objections. It is not a legal requirement to continue a child's life-sustaining treatment in all circumstances. For example, where the child is suffering an illness where the likelihood of survival even with treatment is extremely poor, and treatment will pose a significant burden to the child, it may not be in the best interests of the child to continue treatment.

### Adults and children lacking capacity

10. If a child lacks capacity, it is still good practice to involve the child as far as is possible and appropriate in the decision. The decision to withdraw or withhold life-sustaining treatment must be made in the best interests of the child. The best interests of a child in the context of the withholding of medical treatment should be interpreted more broadly than medical interests, and should include emotional and other factors. There is a strong presumption in favour of preserving life, but not where treatment would be futile, and there is no obligation on healthcare professionals to give treatment that would be futile. If there is disagreement between those with parental responsibility for the child and the clinical team concerning the appropriate course of action, a ruling should be sought from the court as early as possible. This requirement was emphasised in the *Glass* judgment (see chapter 3, paragraph 21).
11. A person with parental responsibility for a child or young person is legally entitled to give or withhold consent to treatment. A person with parental responsibility cannot demand a particular treatment to be continued where the burdens of the treatment clearly outweigh the benefits for the child. If agreement cannot be reached between the parent(s) and the healthcare professionals, a court should be asked to make a declaration about whether the provision of life-sustaining treatment would benefit the child. In exceptional cases, the court has been willing to authorise the withdrawal of life-sustaining treatment against the parents' wishes.<sup>64</sup> However, the views of the parents are given great weight by the courts and are usually determinative unless they conflict with the child's best interests.
12. If an adult lacks capacity, and has not made a valid and applicable advance decision to refuse life-sustaining treatment, the provisions of the Mental Capacity Act will apply and the decision must be based on the best interests of the adult, again involving the person as far as this is possible.

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<sup>64</sup> *Re C (medical treatment)* [1998]

13. As with all decisions made under the Mental Capacity Act, before deciding to withdraw or withhold life-sustaining treatment, the healthcare professional must consider the range of treatment options available in order to work out what would be in the person's best interests. All of the factors set out in the Mental Capacity Act (2005) Code of Practice should be considered, and in particular the healthcare professional should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment. Healthcare professionals should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.
  
14. Where a patient had indicated, while they had capacity, his or her wish to be kept alive by the provision of ANH, the doctor's duty of care will require the doctors to provide ANH while such treatment continues to prolong life. Where life depends upon the continued provision of ANH, ANH will be clinically indicated. If the patient lacks capacity, all reasonable steps that are in the person's best interests should be taken to prolong their life. Although there is a strong presumption in favour of providing life-sustaining treatment, there are circumstances when continuing or providing life-sustaining treatment stops providing a benefit to a patient and is not clinically indicated.<sup>65</sup>

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<sup>65</sup> *Burke v the General Medical Council* [2005] 3 WLR 1132

# 5 Other exceptions to the principles

1. Certain statutes set out specific exceptions to the principles noted in the previous chapters. These are briefly noted below. Those concerned with the operation of such statutes should consult more detailed guidance.
2. Part 4 of the Mental Health Act 1983 ('the 1983 Act') sets out circumstances in which persons liable to be detained under the Act may be treated without consent for their mental disorder. The 1983 Act has no application to treatment for physical disorders unrelated to the mental disorder, which remains subject to the common law principles described in previous chapters, even where the person concerned is detained under the Act. The Mental Health Act Code of Practice offers guidance on consent and medical treatment in this context.<sup>66</sup>
3. Neither the existence of mental disorder nor the fact of detention under the 1983 Act should give rise to an assumption of incapacity. The person's capacity must be assessed in every case in relation to the particular decision being made. The capacity of a person with a mental disorder may fluctuate.
4. Significant amendments to the 1983 Act have been made by the Mental Health Act 2007.<sup>67</sup> The 1983 Act will continue to provide legal authority, within certain limits and subject to certain safeguards, to treat detained patients for mental disorder without consent. Except in emergencies, however, it will no longer be permissible to use the 1983 Act to administer electro-convulsive therapy (ECT) to a patient who has capacity to consent to it, but who does not. Additionally, if a person made an advanced decision when they had capacity, saying that they never wished to receive ECT and the hospital knows about this, then the treatment cannot be given. The only exception would be in an emergency if it was immediately necessary to save a patient's life or to prevent a serious deterioration of the patient's condition.
5. In addition, except in emergencies it will not be permissible to administer ECT as a treatment for mental disorder in any circumstances to any child or young person under the age 18 (whether or not they are otherwise subject to the 1983 Act) unless it

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66 Department of Health (2008) *Code of Practice: Mental Health Act 1983*. London: DH. [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_084597](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084597)

67 Mental Health Act 2007. [www.opsi.gov.uk/acts/acts2007/pdf/ukpga\\_20070012\\_en.pdf](http://www.opsi.gov.uk/acts/acts2007/pdf/ukpga_20070012_en.pdf)

has been independently approved in accordance with the 1983 Act. Further guidance is given in the Mental Health Act Code of Practice.<sup>68</sup>

6. There will also be a new procedure by which certain patients discharged from detention under the 1983 Act can be made subject to community treatment orders (CTOs), making them liable to recall to hospital for further treatment if necessary. While patients are subject to CTOs they may only be treated for mental disorder in accordance with the 1983 Act. Unless they have been recalled to hospital, it will not be permissible to treat such patients without their consent if they have the capacity to consent to the treatment in question but do not do so. Treatment for mental disorder of patients subject to CTOs who lack capacity to consent will be permitted, subject to the rules set out in the new Part 4A of the 1983 Act.
7. It will remain the case that no-one (whether or not detained under the 1983 Act) may be given neurosurgery for mental disorder ('psychosurgery') or have hormones surgically implanted in order to reduce male sex drive, unless they consent to the procedure and it has been independently approved in accordance with section 57 of the 1983 Act.
8. None of these changes will affect the principle that treatment for physical disorders, unrelated to the mental disorder for which the patient is receiving compulsory treatment, does not come within the scope of mental health legislation.
9. The Public Health (Control of Disease) Act 1984 provided that, on an order made by a magistrate, persons suffering from certain notifiable infectious diseases could be medically examined, removed to and detained in a hospital without their consent. A magistrate when ordering the detention of a person in a hospital could not order that a person undergo medical treatment. The treatment of such persons must be based on the common law principles previously described. The 1984 Act is now amended by the Health and Social Care Act 2008. Under part 2A there is express provision prohibiting regulations under new sections 45B or 45C from legislating for the administering of medical treatment by force. Nor will there be power for a magistrate to order compulsory treatment under new section 45G, which gives powers to magistrates to make orders in relation to persons who pose a threat to the health of others.

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<sup>68</sup> Department of Health (2008) *Code of Practice: Mental Health Act 1983*. London: DH.  
[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_084597](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_084597)









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296926 1p 0k July 09 (web)  
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