

Third edition
incorporating guidance
on the Mental Capacity Act

Withholding and Withdrawing Life-prolonging Medical Treatment

Guidance for decision making

THIRD EDITION

British Medical Association

BMA 

 **Blackwell
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Withholding and Withdrawing Life-prolonging Medical Treatment

Guidance for decision making

Medical Ethics Committee

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Acknowledgements for the third edition

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Introduction

In medicine, decisions are made on a daily basis about the provision, withholding or withdrawing of treatments, some of which could prolong life. Treatments which might provide a therapeutic benefit are not inevitably given but are weighed according to a number of factors, such as the patient's wishes, the treatment's invasiveness, side-effects, limits of efficacy and the resources available. The Intensive Care Society has estimated that approximately 50,000 patients are admitted to intensive care units in England and Wales each year. Of these, 30% (15,000 patients) die without leaving hospital, most as a result of active treatment being withdrawn [1].

Although not uncommon, few issues in medicine are more complex and difficult than those addressed by patients, their relatives and their doctors concerning the decision to withhold or withdraw potentially life-prolonging treatment. Technological developments continually extend the range of treatment options available to prolong life when organ or system failure would naturally result in death. Cardiopulmonary resuscitation, renal dialysis, artificial nutrition, hydration and ventilation prolong life and, in some cases, allow time for recovery but these techniques cannot, in themselves, reverse a patient's disease. Patients with progressive conditions such as motor neurone disease can have their lives prolonged by the application of technology, but their underlying illness cannot be cured and deterioration in their condition is unavoidable. The condition of other patients, for example those with very severe brain damage, may remain stable for many years if life-prolonging treatment is provided but they may have no hope of recovering more than very minimal levels of awareness of their surroundings. They may lack the ability to interact with others or capacity for self-awareness or self-directed action. In such severely damaged patients, interventions to prolong life by artificial means may fail to provide sufficient benefit to justify the burdens of intervention (see Section 9) and the proper course of action may be to withhold or withdraw further treatment.

Most people accept that treatment should not be prolonged indefinitely when it has ceased to provide a benefit for the patient. But patients and their families, doctors and other members of the clinical team and society as a whole need reassurance that individual decisions are carefully thought through, based on the best quality information available and follow a widely

agreed procedure. Decisions need to be made on an individual basis, assessing the particular circumstances, wishes and values of the patient to ensure that treatment is neither withdrawn too quickly nor unnecessarily prolonged. It is essential that there are clear, robust and transparent procedures for making these decisions. The BMA is very pleased to note that, over recent years, comprehensive guidance has been developed outlining the criteria and steps to be followed in making these decisions, particularly where difficult assessments are required about the best interests of incapacitated patients. In addition to the BMA's guidance, first published in 1999, there is now also detailed advice from the General Medical Council [2] and from the Royal College of Paediatrics and Child Health [3]. There is also statutory guidance for those providing treatment for adults who lack capacity, in the form of Codes of Practice under the Adults with Incapacity (Scotland) Act 2000 [4] and the Mental Capacity Act 2005 [5]. Nevertheless, there is only benefit in having guidance if it is available to, and used by, those responsible for making these decisions. Occasional media reporting has served to remind us that best practice is not yet universal and that we all have a responsibility to ensure that good communication and decision-making procedures are followed in all cases. In this document, the BMA seeks to provide a coherent and comprehensive set of principles which apply to all decisions to withhold or withdraw life-prolonging treatment. It is hoped that this general guidance will stimulate the development of accessible local policies and guidelines as part of a wider network of safeguards for doctors and patients.

The need for guidance in this area became clear from a wide-ranging consultation exercise undertaken by the BMA in 1998. This led to the first edition of this guidance being published in 1999. A second edition was published in 2001 to incorporate specific guidance on the impact of the Human Rights Act. This third edition includes subsequent developments in legislation – specifically the Mental Capacity Act (which at the time of writing was due to come into force in 2007) – and the common law. Although these changes have clarified some aspects of the law, some legal uncertainties remain and judicial review will still be required in particular cases. Part of the aim of this guidance is to identify the type of cases where decisions may be made by the patient, the health care team and/or those close to the patient and those where a declaration from a court is required. This guidance does not set out to give definitive legal advice but to explain the legal and ethical principles that underpin decision making in this area and to help health professionals to recognise when further advice is needed. Of course, the law will not remain static and information about any major developments following publication will be posted on the BMA's website at www.bma.org.uk/ethics.

We hope that this guidance will give confidence to those required to make these difficult decisions and the families of those on whose behalf the decisions are made. The importance of good communication at all stages of the decision-making process cannot be overstated and this forms a central part of our guidance. At the time of writing the Mental Capacity Act 2005 was scheduled to come into force in two stages – in April and September 2007. For more information on the implementation of the Act, see the BMA's website at: www.bma.org.uk/ethics.

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Part 1 **How to use this guidance**

1. Scope, purpose and structure of this guidance

1.1. This document covers a wide range of different scenarios, treatments, patients and UK jurisdictions. With this in mind some parts of the guidance cover the general moral, legal and practical issues that apply to all decisions while other sections provide more specific information enabling readers to quickly identify the information they need.

We recommend that Parts 2, 3 and 4 of this guidance be read first as they set the scene for decision making, define the concepts and definitions used throughout and address the practical considerations that apply to all decisions. From Part 5 onwards the guidance is divided up into sections based on whether the patient is an adult who has or lacks capacity or a child or young person who has or lacks capacity. Clearly there is overlap and some repetition is inevitable but cross-referencing is used wherever possible. Although we have tried to give a clear indication of the important factors to consider with each type of patient, information that is provided in other sections may also be helpful in giving an overall picture of the decision-making process.

Summary boxes have been included throughout the text to ease navigation through the guidance and legal cases are summarised to illustrate the relevant legal points. Although some of these cases are now quite old and were decided before the Human Rights Act and mental capacity legislation came into force, they remain important in guiding both legal and medical practice.

This guidance is intended to complement, and not replace, statutory guidance issued under mental capacity legislation. It is essential that all health professionals, who are working in England, Wales and Scotland with adults who lack capacity, are familiar with the statutory Codes of Practice published under the Mental Capacity Act 2005 and the Adults with Incapacity (Scotland) Act 2000.

1.2. The main focus of this guidance is decisions to withdraw or withhold life-prolonging treatment from patients who are likely to live for weeks, months or possibly years, if treatment is provided but who, without treatment, will or may die earlier. In some areas mention is also made of treatment decisions for those patients whose imminent death is inevitable.

2 *How to use this guidance*

This guidance focuses on the process through which decisions are made to withdraw or withhold life-prolonging treatment from all types of patients – adults with capacity, adults lacking capacity, young people with capacity and children and young people who lack capacity. Such decisions are taken on a regular basis, throughout the country where, for example, patients with capacity decide that, for them, the burdens of further aggressive chemotherapy or dialysis outweigh the potential benefits. Or, where patients lack capacity, it is judged that invasive treatment would not be in their best interests because it is unable to provide a level of recovery that would justify the intervention. Similarly, a decision may be made that, in the event of cardiac arrest, a patient should not be subjected to cardiopulmonary resuscitation because the chances of recovery, or the level of recovery that could reasonably be expected, would not provide a net benefit to that patient. These decisions are always profound and cannot be taken lightly. The intention of this guidance is to set down established good practice in this area to help all those involved with making such decisions.

1.3. This document is not an attempt to define rules which must be followed. Rather, it provides general guidance about the principles and factors to take into account in reaching a decision.

This guidance does not provide a simple set of instructions to be followed without reflection but a tool to inform and aid decision making; it does not provide easy answers but offers an approach through which an appropriate decision may be reached. It reflects the standards that doctors must meet, as required by law and set out by the General Medical Council, and sets these standards within a broader context with a view to providing practical advice for decision making. Although principally aimed at health professionals, others who are responsible for decision making, such as the parents of young children and those who are appointed as personal welfare attorneys or deputies for incapacitated adults, may also find this guidance useful. This document provides a basis for discussion between all those involved in making decisions, which will include health professionals, the patient and those close to or representing the patient.

Part 2 **Defining key terms and concepts**

This section defines some of the key terms and concepts that are used throughout this document. It is useful to read through this section to provide general information about, and set the scene for, decision making before moving on to the more specific information provided in later sections. In order to minimise repetition these definitions are not repeated later in the text and so it is also necessary to refer back to these definitions when reading later sections of the guidance.

2. The primary goal of medicine

2.1. The primary goal of medical treatment is to benefit the patient by restoring or maintaining the patient's health as far as possible, maximising benefit and minimising harm. If a patient with capacity has refused the treatment or if the patient lacks capacity and the treatment would fail or ceases to provide a net benefit to the patient, then that goal cannot be realised and the treatment should, ethically and legally, be withheld or withdrawn. Good quality care and palliation of symptoms should, however, continue.

Health care is normally based on the common sense assumption that life-prolonging treatment is beneficial and that most patients would want it. In the majority of cases, therefore, it is provided unless the patient refuses it or the patient's death is imminent and inevitable. There are, however, some extreme cases where life-prolonging treatment fails to provide a net benefit to the patient because it is unable to achieve a level of recovery that justifies the corresponding burdens of the treatment. Or, the treatment may keep the patient alive but be unable to stop the progression of the disease or provide any hope of the patient recovering self-awareness, awareness of others and the ability to intentionally interact with them (see Section 9). Patients sometimes decide that the stage has been reached beyond which, for them, continued treatment aimed at prolonging life, although possible, would be inappropriate. Where patients lack capacity, these decisions must be taken in a way that reflects their wishes or, if these are not known, their best interests. This may include a decision not to provide or continue to provide an intervention