

## 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.