4 - Guidance on *Treatment and Care towards the End of Life: Good Practice in Decision Making*
Annex B

The Development of the Guidance *Treatment and Care towards the End of Life: Good Practice in Decision Making*

Outcome of the scoping exercise

1. The scoping exercise drew together the developments since the guidance was published in 2002. These included:

   a. Case law – new precedent cases have been hear on issues such as the factors to consider in decisions about providing potentially life prolonging treatments to very sick children; how human rights law impacts on medical decisions; and including the 2005 Court of Appeal judgment in Burke v GMC which dealt with advance requests for treatment.

   b. Legislation - the Mental Capacity Act 2005 (England and Wales) established a framework for making health and personal care decisions for adults who lack capacity to decide.

   c. Reports on poor practice - for example Mencap's report 'Death by Indifference' (March 2007) and the Joint Committee on Human Rights report ‘The human rights of older people in healthcare’ (August 2007), which highlighted serious shortcomings in the standards of end of life treatment and care provided to elderly and disabled patients in some healthcare settings.

   d. Changing public policy – Governments across the UK has placed priority on improving the availability and quality of palliative and end of life care for all patients, including ensuring that doctors have the knowledge, skills and support needed to deliver better standards of care.

The underlying ethical principles (paragraphs 7-12 of the guidance)

Equalities and human rights

2. We also make clear the obligation on doctors to treat patients without discrimination and to respect their rights to dignity and privacy. This is reinforced in other sections of the guidance where we make clear that doctors must consider the individual circumstances of each patient; they must not make judgements based on poorly informed or unfounded assumptions about the healthcare needs of particular groups, such as older people and those with disabilities.

Presumption in favour of prolonging life

3. The guidance recognises that treating patients towards the end of their life can be clinically complex and some of the options may raise difficult ethical and legal questions which add to the complexity of the decision making. We have made more explicit in this guidance that, when providing care, a doctor must not be motivated by a desire to bring about the patient's death, and must start from a presumption in favour of prolonging life. However this does not mean that life-prolonging treatment must always be provided, regardless of the patient's wishes or the burdens and risks it may bring.

Presumption of capacity and maximising capacity to decide

4. Patients who are coming to terms with a situation where they may be approaching the end of life are likely to need help and support to understand the issues and be able to make decisions. The guidance stresses the importance, when dealing with patients, of starting from a presumption of capacity, and a doctor's duty to work with patients to maximise their capacity to make their own choices and make their views and wishes known.

Maximising capacity to make decisions

5. This has been included as it is a key provision of the capacity legislation in England, Wales and Scotland, and ensures that patients' rights to participate in, or to make decisions for themselves are respected.

The role of relatives, partners and others close to the patient (paragraphs 17-21 of the guidance)

6. New guidance on the role of those close to the patient has been introduced to recognise the significant role played by parents, family members and others in caring for patients and in the decision-making process.

The challenges in decision-making and advance care planning (paragraphs 50-62)

7. The guidance acknowledges the many complexities that doctors might face when decisions have to be made about treatment and care of patients who may be approaching the end of life. It gives advice to doctors on dealing with the clinical uncertainties (including predicting how long a patient might live with life-threatening or terminal condition); the emotional distress that patients and others might be experiencing (including members of the healthcare team); meeting the communication challenges when patients or those close to them may be having difficulties coming to terms with the situation; and working in partnership across service boundaries to ensure that the individual needs of patients can be met.

8. A cornerstone of this approach is the advice about advance care planning. The guidance highlights the benefits of holding early discussions with patients about their future care. It can help to avoid the problems caused by communication failures, and ensure that patients' individual wishes, preferences and values are respected and taken into account in decisions that need to be made when the patient has lost capacity. Doctors can use advance care planning to ensure that arrangements are in place to support team working across the different settings in which a patient is likely to receive care. The guidance offers support to doctors in approaching these sensitive conversations with patients. It highlights the possibility of formalising a patient's wishes into an advance statement or advance refusal of treatment, if that is what the patient wants.

9. In response to feedback from the public: the guidance also encourages doctors to create opportunities for patients who want to, to discuss their wishes about what should happen to their body after they die, including the possibility of organ and tissue donation.

Advance requests for treatment (paragraphs 63-66 of the guidance)

10. Patients may have concerns about how treatment will be decided if they lose capacity to make their own choices or communicate their wishes. This may lead some to make requests for a particular treatment, especially if the patient attaches special importance to that treatment. The guidance discusses how doctors should deal with these situations. It makes clear that doctors must offer treatment which they assess to be clinically appropriate. They must give weight to a patient's previous request for treatment in decisions about what would be of overall benefit; and where consideration of all relevant factors does not yield a clear answer, the patient's request should usually be the deciding factor. This advice is carried through into the guidance on CANH and CPR.

Organ donation (paragraphs 81-82 of the guidance)

11. We have responded to professional and public interest in having guidance about organ and tissue donation that encourages discussion, but does not compel doctors to raise the issue when they judge that it would not be appropriate to do so. Detailed guidance about the law and other factors surrounding donation is provided by the Human Tissue Authority and others, and these are flagged in the reference section.

Care after death (paragraphs 83-84 of the guidance)

12. The guidance makes clear that a doctor's responsibility does not end when a patient dies. It covers a range of concerns raised by doctors and the public, including information about the responsibility to support bereaved family, carers and others close to the patient; respect for the patient's body (for example taking account of cultural and religious considerations); and doctors' duties in relation to death and cremation certification.

Neonates, children and young people (paragraphs 90-98 of the guidance)

13. The guidance emphasises the role of parents in decisions about the treatment and care of their children. It makes clear that doctors must involve them in discussions; listen to and respect their views and understanding about their child's feelings and condition; and be sensitive to parents' concerns and anxieties about withdrawing or not starting potentially life-prolonging treatment. Doctors must make sure children and their parents have the information and support they need, when facing these difficult decisions.

14. The guidance highlights the particular clinical complexities and emotional challenges involved in reaching a view about the benefits, burdens and risks of treatment for very young children, especially extremely premature neonates and infants. It emphasises the need to base decisions on up to date authoritative clinical guidance, seeing advice or a second opinion as early as possible, and ensuring that any distressing symptoms that the patient may be experiencing are being effectively managed.

What we have expanded in the guidance

Advance refusals of treatment (paragraphs 67-74 of the guidance)

15. The guidance discusses how doctors should deal with situations where it comes to light that a patient has made an advance refusal of treatment. There are significant differences in the law relating to advance refusals of treatment in the UK jurisdictions. However, we are satisfied that this ethical guidance is consistent with the law across the UK.

Nutrition, hydration and clinically assisted nutrition and hydration (paragraphs109-127 of the guidance)

16. In recent years there has been a great deal of public concern about the standard of nutritional care that may be provided to patients who are approaching the end of life, in some healthcare settings. The guidance stresses the importance of meeting patients' needs for help to eat and drink; doctors' responsibilities in addressing situations where patients are not receiving that help; and the need to keep patients' nutrition and hydration status under review.

17. The guidance also acknowledges the clinical complexities and other challenges that doctors may face when decisions have to be made about providing nutrition or hydration by drip or tubes (‘clinically assisted’ nutrition and hydration). These decisions are often contentious when patients are approaching the end of life, not least where patients have strongly held views about receiving nutrition or hydration.

18. The guidance makes clear that, doctors must make separate assessments of a patient’s needs for clinically assisted nutrition or hydration. They must pay particular attention to the importance of listening to the views of the patient (and those close to a patient who lacks capacity), helping them to understand how other aspects of the patient’s care will be managed whatever decision is made about clinically assisted nutrition or hydration. If a patient makes an advance request for clinically assisted nutrition or hydration, doctors must give this weight in the decision about overall benefit and, when the benefits, burdens and risks of treatment are finely balanced the patient’s request will usually be the deciding factor.

19. The guidance makes clear that decisions about withdrawing or not starting clinically assisted nutrition and hydration, in cases where the patient lacks capacity to decide, are governed by the same principles that apply to all other medical treatments. In addition making a decision to withdraw or not start clinically assisted nutrition or hydration because the burdens and risks of providing the treatment outweigh any benefits - where the decision could be seen as leading or contributing to a patient’s death - appears to be consistent with the provisions of the capacity legislation in England, Wales and Scotland, and the common law approach to best interests decisions which applies in Northern Ireland. However this point has not been tested in law, which may cause some concern about whether the decision making process adequately protects the rights and interests of patients in these circumstances. For this reason, the guidance requires doctors to include an additional step in the decision making process, before reaching a final view about whether to withdraw or not start clinically assisted nutrition or hydration in these circumstances. Doctors must seek an independent second opinion (based on an examination of the patient) from a senior clinician who is not already directly involved in the patient’s care (allowing for exceptional circumstances where this would not be possible or practical). Doctors are advised to consider seeking legal advice, before acting on a decision and, if clinically assisted nutrition or hydration is withdrawn, they must keep the patient’s condition under review and be prepared to reassess whether the treatment would be of overall benefit to the patient.

20. Given the particular sensitivities and challenges involved in decisions about CANH, we will be providing a range of case study illustrations of how the guidance might be applied in different circumstances. One illustrative example will be published with the online version of the guidance; one will be included in the e-learning session on e-ELCA; and others will be developed as part of our longer term implementation programme.

Cardiopulmonary resuscitation (paragraphs 97-110)

21. Doctors and patients, for different reasons, want greater clarity on when it might be appropriate to consult or inform a patient about decisions not to attempt CPR. The guidance discusses when it might be appropriate to consider making a Do Not Attempt CPR decision (DNACPR), and makes clear that the same principles apply to these decisions as to all other treatments. Where there is a balancing of benefits with burdens and risks, the patient's wishes and preferences must be taken into account.

22. Doctors are not expected to seek a decision from a patient with capacity, about a treatment that will not be offered because it is not clinically appropriate. Unusually in the case of CPR a decision, that it should not be attempted because it is not clinically appropriate, has to be made known to the healthcare team and recorded as part of the patient's care plan. If the patient isn't informed, it is possible the patient will become aware of the decision, either in the setting where the decision is made or if they transfer to another setting where their carers (family and others) are informed about the DNACPR. Patients finding out in this way may be very distressed that they were not told about the decision, and issues about respect for their autonomy may arise.

23. The guidance strikes a balance between doctors' responsibility not to withhold relevant information from a patient who has capacity to decide, and not to force potentially distressing information on a patient who indicates that they do not want to know. It makes clear that doctors must provide the opportunity for patients to discuss CPR if they wish to do so. While it is not necessary to ask a patient to discuss CPR when it will not be offered because it is not clinically appropriate, nevertheless it may be appropriate to inform them of the decision, or seek their agreement to share relevant information with their carers.

24. In the case of patients who lack capacity to decide, the guidance makes clear that it is necessary and appropriate to consult, or inform, those close to the patient about DNACPR decisions. When the benefits, burdens and risks are finely balanced, a patient's request for CPR should usually be the deciding factor.