

End of life treatment and care: good practice in decision making

Questions relating to the draft guidance

Introduction (paragraphs 9-12)

In this section we explain what we mean by 'life-limiting conditions' and 'end of life care'. It sets out the types of situations and cases the guidance is intended to cover, as well as flagging up the importance of broader care issues such as palliative care.

1. Do you agree that the Introduction (paragraphs 9-12) sets out the scope of the guidance clearly?

Yes No Not sure

Comments

In general we agree that the Introduction sets out the scope of the guidance well. We appreciate the change of focus from the narrow question of 'withholding and withdrawing treatment' as contained in the previous guidelines, to the broader context of 'end-of-life care'. It is especially good to see explicit mention of social and spiritual support for patients in this context (para 10).

One area of concern is in the characterising of those in PVS and conditions that 'resemble' this as 'life limiting' conditions (para 9d). Clearly disability of all kinds, and particularly cognitive impairment, can limit one's ability to function in life. However, as is pointed out elsewhere in the document (e.g. para 14), there is a duty on doctors to ensure that all patients receive an adequate standard of care. The document in general shows a good balance in protecting the rights of patients to receive adequate care while acknowledging their right in law to refuse unwanted burdensome or futile treatment. The classification of PVS patients alongside those who are 'dying' is a confusion that endangers their right to equal respect. This has particular relevance to the issue of nutrition and hydration.

Equalities and human rights (paragraphs 13-15)

Human rights principles and equalities law have particular importance in decisions about end of life care. This section of the guidance is intended to highlight this point. The guidance here is in terms of high level principles. Other parts of the guidance address how these principles apply in practice.

2. Do you think there other general problems or issues in relation to equality, diversity and human rights that we should flag up in this section?

Yes No Not sure

Comments

It is good that the guidance is explicitly drawing attention to the human rights of patients. This can be a helpful way to express the ethical duties of a doctor towards his or her patients, duties that in the Catholic tradition have sometimes been expressed in terms of the 'natural law'.

One area of human rights that could helpfully be made explicit is the area of diversity and discrimination, especially in relation to belief. Respect is due to patients and doctors in relation to their beliefs. This does not justify every possible expression of belief, but it does underlie such importance principles as the protection of conscientious objection. It also informs decisions about 'overall interest'.

Presumption in favour of prolonging life (paragraph 16)

Paragraph 16 sets out the principles which underpin the advice in later parts of the guidance, in particular the section on assessing the overall benefits of treatment options (paragraphs 36-41). It emphasises the presumption in favour of prolonging life and the need to balance this with the consequences for the patient and the patient's own wishes about treatment. We believe that the advice in paragraph 16 strikes a reasonable balance between ensuring:

- a. patients receive treatment where they need and want it; and
- b. patients who are dying are treated with dignity and not subjected to burdensome treatment.

In answering the following question, you may find it helpful to also consider the advice in paragraphs 36-41

3. Do you agree that the advice in paragraph 16 strikes a reasonable balance between these factors?

Yes No Not sure

Comments

This is an extremely important statement of principle and strikes a good balance between the general duty to prolong life and the need to respect refusals of burdensome treatment. It is particularly good in first excluding the intention to bring about death as an acceptable reason for withdrawal of treatment. It is good that this prohibition is distinguished from the presumption that positive steps should be taken to extend life. This presumption is strong but does not apply in all circumstances. The guidance rightly allows withholding of life sustaining treatment in some circumstances where the intention is not to bring about death.

The phrase ‘motivated by a desire to bring about the patient’s death’ is not as clear as ‘aimed at’ ‘intended to’ or ‘in order to’ but it has the advantage of echoing the mental Capacity Act 2005. This paragraph is currently very strong but could be further improved if ‘motivated by a desire to bring about the patient’s death’ was quoted but then clarified as meaning ‘aimed at’ ‘intended to’ or ‘in order to’.

Making sound clinical judgements (paragraphs 21-24)

This section of the guidance reminds all doctors, even those with considerable experience, about key difficulties in practice that are not always recognised outside palliative care. One well known difficulty is diagnosing how long a patient has to live. Another problem is that many doctors think of palliative care as something that is only relevant to the last days of life. The guidance encourages doctors to think, at an early stage, about the likely progression of a patient’s condition and the need to think about and plan for palliative care.

4. Do you think the guidance will prompt doctors to think early enough about the likely progression of a patient’s condition and the need to plan for palliative care? If not, please include any suggestions for how the guidance could achieve this.

Yes **Y** No Not sure

Comments

It is good that doctors are prompted to think early of a patient’s palliative care needs. Palliation is not confined to the time after attempts to cure have ceased, but rather every patient has symptom control and care. It would be good if spiritual care, which is mentioned in paragraphs 10 and 46f was also mentioned in paragraph 22. Attention to spiritual needs should not be confined to the last few days of life but be an element of care offered to every patient.

Paragraph 22 highlights the need to give early consideration to the patient’s palliative care needs, and to consider how to manage any pain, breathlessness, agitation or other distressing symptoms that they may be experiencing. It also gives advice on what doctors should do if they are uncertain about how to meet patients’ needs.

5. Do you think that the guidance is sufficient to ensure that patients’ needs for symptom management and pain relief will be met adequately, regardless of where they are receiving care?

Yes No Not sure **NS**

[Comments]

Explaining the clinical issues; addressing uncertainty; emotional difficulties in end of life decision making (paragraphs 25-32)

The clinical issues towards the end of a patient's life can be complex, and it may not be possible to arrive at clear decisions without starting treatments which then have to be withdrawn. The scope for misunderstanding (between patients, carers and members of the healthcare team) about the clinical issues is high. This can be further complicated by the emotional distress that patients and carers and members of the healthcare team might be facing at the time. The advice at paragraphs 25-32 is intended to highlight these problems and suggest helpful ways for doctors to respond.

6. Do you think the guidance will lead to more patients, family members and carers receiving the support they want and need when they are coping with complex or distressing information?

Yes **Y** No Not sure

[Comments]

7. Do you think that these sections include sufficient advice about good communication and means of supporting patients, those close to them and members of the healthcare team?

Yes No **N** Not sure

Comments

There is good advice here but paragraph 25 should also include the statement that some people consider clinically assisted nutrition and hydration to be basic care rather than treatment.

Furthermore, it would be helpful if paragraphs 30-32 also drew attention to spiritual care and the role of chaplains in clarifying religious teachings to help families making decisions. Conversation with a trusted religious representative from the patient's own tradition can bring clarity and reassurance about the difficult decision to withdraw treatment.

Resource constraints (paragraphs 33-35)

We have expanded on existing GMC advice on resource constraints. The guidance sets out what we believe are the key points that doctors should take into account, to ensure that they address the full range of ethical issues in any given situation.

Note: this guidance is not intended to cover situations of national emergency, such as a flu pandemic, which is covered by other guidance.

8. Can you think of any other situations or cases that could not be dealt with effectively by following the guidance? If yes, please tell us what these are.

Yes No Not sure **NS**

Comments

The area of resource constraints is an important one that many patients worry about and it is good that the GMC is explicit about this. The overall approach to the question in the guidance is sound and it is good to see doctors encouraged to raise issues of patient safety where allocation decisions put this in danger.

Assessing the overall benefits of treatment options (paragraphs 36-41)

For some people, it can be difficult to understand or accept that the ethical and legal duty to protect life can be outweighed by other considerations. The guidance in paragraphs 36-38 sets out the circumstances where a potentially life-prolonging treatment might not be provided (expanding on paragraph 16), including towards the end of life when the focus of care should change from active treatment to ensuring that a patient's dignity is respected and they are kept comfortable and their pain and other symptoms are properly managed. Paragraphs 36-38 should be read alongside paragraph 16, which sets out the underpinning principles.

9. Do you agree that this guidance provides a sufficiently clear basis for reaching sound judgements about when to withdraw or not to start a potentially life – prolonging treatment?

Yes **Y** No Not sure

Comments

Paragraphs 41 and 42 are very well-balanced.

Advance care planning (paragraphs 42-52)

This section provides information about the benefits of holding early discussions about future care, with patients and their families. It highlights the issues we believe patients may want to explore, and points to sources of help for doctors in managing these conversations.

10. Do you agree that paragraphs 42-52 include all of the key issues that are relevant to advance care planning? If not, please tell us what other issues should be included.

Yes **Y** No Not sure

Comments

The guidance takes an admirably prudent approach in strongly advocating advance care planning but in neither encouraging nor discouraging ‘advance refusals’ and the appointment of a health and welfare ‘attorney’. Doctors should make patients aware of the law but it would be imprudent to make any general recommendation on advance refusals or attorneys.

Acting on advance requests for and refusals of treatment (paragraphs 53-60)

This section sets out general principles about how doctors should approach situations where a patient who has become incapacitated had previously requested that a particular treatment be continued in the current circumstances or had made an advance decision to refuse a particular treatment.

In paragraph 55 we address situations where the treatment is already being provided and the patient is a few days/or hours away from death. The guidance provides that it is usually appropriate to stop the treatment (while focusing on meeting the patient’s needs for palliative care and symptom management) where the burdens continuing the treatment outweigh the possible benefits. However, where the patient has previously expressed a wish for the treatment to continue in these circumstances, the guidance says that doctors must weigh up the harm that might be caused by:

- a. going against the patient’s wishes; and
- b. continuing to provide the treatment

in reaching a decision about what course of action would be of overall to the patient.

11. Do you agree that going against the patient’s advance wishes to receive a particular treatment should be treated as a potential harm to be weighed with the other factors, in deciding what course of action is of overall benefit to the patient?

Yes **Y** No Not sure

Comments

There is no absolute right to receive treatment of limited or no clinical benefit and the final decision in the Burke case was correct in this regard. Nevertheless, the benefits and burdens of treatment will be relative to the patients and this in part determines ‘overall benefit’. The doctor contributes to the assessment of overall benefit though clinical expertise as to risks, likely benefits and burdens, but how these are weighed will always involve a subjective element.

Furthermore some treatments have a significance for patients in addition to their clinical value, this is especially true of assisted nutrition and hydration. The symbolic value as an expression of worth or of human solidarity may remain even if the ability to contribute to nutritional need is in fact limited so long as it does not itself endanger health. In this precise context the withdrawal of clinical assisted nutrition or hydration against the patient's wishes is definitely a harm.

12. Can you think of any obstacles to following the guidance in respect of particular treatments or in different settings, including where care is provided in the patient's home?

Yes No Not sure **NS**

[Comments]

Paragraphs 55-60 cover advance refusals of treatment. The advice in this section takes account of differences in the laws and codes of practice governing advance refusals of treatment, across the UK. We have done our best to set out the issues in a clear, uncomplicated way and avoid repeating detail from the codes of practice.

13. Do you think the guidance makes clear how doctors should decide whether a patient's advance refusal of treatment should be acted on?

Yes **Y** No Not sure

[Comments]

Paragraphs 59 and 60 are expressed clearly and are very important.

Recording and communicating decisions (paragraphs 62-65)

This section provides advice on the importance of clear lines of communication between members of the healthcare team about the decisions made and actions taken in relation to patients. These principles apply to all patients but those who are dying will often move between different care settings and come into contact with a range of health and social services where care is provided by multi-disciplinary and multi-agency teams. It is, therefore, particularly important in this context that there is good communication and that lines of accountability and responsibility are clear. The guidance in paragraphs 61-64 aims to address the factors which can help and hinder the provision of good care to patients in these circumstances.

14. Do you think that there are other factors that can help or hinder timely and clear sharing of information between everyone involved in a patient's care?

Yes No Not sure **NS**

[Comments]

Conscientious objections (paragraph 67)

This paragraph gives advice about situations where a doctor's personal beliefs (rather than their clinical judgement) conflict with a patient's refusal of treatment or the decision of a healthcare team or consultant not to provide, or to withdraw, a treatment. The guidance makes clear that while a doctor may withdraw from a patient's care in these circumstances, there is an obligation to make sure that arrangements are made for another doctor to take over their role.

The advice does not apply to situations where there is a disagreement based on clinical judgement about whether a treatment should be provided (see paragraph xx of the guidance).

15. Do you agree that the guidance make clear the circumstances in which a doctor can withdraw from a patient's care where they have a conscientious objection to the withdrawal or withholding of a life prolonging treatment?

Yes No **N** Not sure

Comments

The question helpfully distinguishes objections in principle, based on personal belief, from objections based on clinical judgement and treated in paragraphs 42 and 60. However paragraph 67 in the proposed guidance does not make this distinction so clearly, nor does it refer back to paragraphs 42 and 60.

In this area disagreements are far more likely to be over the applicability of *this* advanced decision or the overall benefit to *this* patient than they are to be about general principles. Examples I could think of which would be based on 'personal belief' in this way are: respecting a valid applicable refusal of clinically assisted nutrition and hydration by someone who was not dying, especially someone who was in a 'persistent vegetative state'. Many other decisions seem likely to involve questions of overall interests which are more closely analogous to disputes over clinical judgements.

It is good that conscientious objection is included in this guidance, as it was in the previous guidance and in the code of practice to the mental Capacity Act 2005. However it is not clear how this is to be applied in practice.

16. Can you think of any obstacles that would prevent doctors from following this advice in the different settings in which patients receive care?

Yes No Not sure **NS**

Comments

It is not clear how this applies to junior doctors or other members of the team who do not have overall responsibility for the patient's care. Is it the responsibility of this junior member to organise alternative cover? This seems more naturally a responsibility of the team leader or ultimately of the hospital or trust. The responsibilities of junior and senior team members do not seem equal in this regard and it is the more junior members who are more in danger of suffering discrimination as a result of diversity of belief and who are more in need of the protection of guidance on conscientious objection.

As well as a duty to the patient the employer has at least some level of duty towards staff and colleagues have a duty to one another to respect diversity of belief.

Care after death (paragraphs 68-72)

There have been a number of concerns raised with us in recent years about the way some doctors deal with patients' relatives, including bereavement support and death certification, and about encouraging greater sensitivity to cultural and religious practices. The guidance is intended to ensure that doctors properly consider the issues at the appropriate time.

17. Do you think this section gives sufficient detail about the key issues that need to be considered after a patient's death?

Yes No Not sure **NS**

[Comments]

18. Do you think the guidance will encourage doctors to raise organ donation with those close to the patient without imposing an obligation to raise organ donation when it is not appropriate?

Yes **Y** No Not sure

[Comments]

The advice in paragraph 72 is based on the understanding that the team providing treatment to a patient will not also be responsible for making any decisions about whether the patient would be a suitable candidate for organ donation.

19. Do you agree that this separation of roles will always be practicable?

Yes No Not sure **NS**

Comments

Whether or not it is always ‘practicable’ a separation of roles is a key safeguard to reassure patients. There would be a clear and uncomfortable conflict of interest if the team tasked with increasing the number of donors where the same team responsible for end of life decisions such as withdrawal of ventilation.

Neonates, children and young people (paragraphs 74-82)

This section focuses on the particular anxieties and difficulties when making decisions that affect the lives of children and especially premature babies.

The guidance builds on the advice in *0-18 years: guidance for all doctors*, which sets out all doctors’ obligations towards children and young people, whether or not they routinely see them as patients. *0-18 years* does not specifically deal with end of life decision making but it gives detailed advice on important matters such as assessing capacity, making best interests assessments and resolving disputes.

This guidance does not seek to duplicate that advice but provides some additional advice on some of the particular difficulties that arise when decisions are being made for very ill babies or other children and young people. The guidance seeks to highlight both the clinical complexities and emotional difficulties and signpost to other sources of information available to help doctors making these decisions.

20. Do you know of any particular concerns about the treatment of neonates, children or young people that are not adequately covered in this guidance?

Yes No Not sure **NS**

Comments

The role and responsibility of parents does not seem to be adequately recognised in this guidance. Where a child is too young to decide for him or herself it is not just that parents have ‘an important role in assessing their child’s best interests’ but that they have the right and responsibility as parents to make these decisions. In many cases there will be a range of reasonable views as to what would be in the child’s interest and it is only if the decision falls outside that range and the decision of the parents is clearly unreasonable and harmful that the decision should be taken away from them. It is in the child’s interest to have questions about that interest decided by his or her parents where possible.

Clinically assisted nutrition and hydration (paragraphs 83-97)

We have replaced the traditional term 'artificial' with the term 'clinically assisted' nutrition and hydration (paragraph 85) to address the confusion that seems to be caused for members of the public by the use of the term 'artificial' nutrition and hydration (AN&H). Since neither the techniques/equipment nor the food and water can be accurately described as 'artificial', it seems sensible to find an alternative way of describing the use of tubes, PEGs and cannulas to provide nutrition and hydration. We believe the term 'clinically assisted' makes a better distinction between helping a patient to take food and drink by mouth and using tubes, lines and other clinical interventions to meet patients' nutrition and hydration needs.

21. Do you agree that the term 'clinically assisted' nutrition and hydration is better than 'artificial' in describing the techniques used to feed and hydrate patients who cannot take food or water by mouth, even with support?

Yes No Not sure

Comments

The term 'artificial' nutrition and hydration is misleading as it is not the nutritional and hydration that is artificial (at least in the case of a PEG tube) it is, rather the means of delivery that is clinical. For this reason the phrase 'clinically assisted nutrition and hydration' is a great step forward and helps express the ambivalence many people feel about this area.

It would be helpful, for legal reasons, to clarify when it is first defined that clinically assisted nutrition and hydration does not include spoon feeding (which is 'assisting' but it clearly belongs to care and is not medical or clinical).

There is some evidence that older patients, in care home and hospital settings, may not get the help they need to enable them to eat and drink. There is also concern that in some cases, where patients are unable to take food and drink by mouth, the possibility of providing clinically assisted nutrition and hydration may not be properly considered.

22. Do you think that the guidance in paragraphs 83-84 emphasises clearly enough a doctor's responsibility to establish whether a patient's needs for assistance with oral nutrition and hydration are being met?

Yes No Not sure

These are very important paragraphs to have at the beginning of the section and represent a great improvement on the previous guidance. Previously the right of all patients to adequate food and drink was more assumed than stated. These paragraphs provided a very helpful context to the reflections later on how that need can be met and the benefits and burdens of different kinds of clinical assistance for nutrition and for hydration.

Deciding what forms of assisted nutrition and hydration are appropriate in the treatment and care of an individual patient is often more clinically complex than many people appreciate. In addition, the emotional distress in end of life decision-making can be felt particularly strongly when clinically assisted nutrition and hydration are being considered. This is because some people see these interventions not as medical treatment but as part of basic care. To address these issues, the guidance sets out (in paragraphs 85-87) the clinical uncertainties and other non-clinical factors that can complicate decisions about the needs of individual patients.

23. Do you agree that setting out these complicating factors is helpful?

Yes **Y** No Not sure

Comments

The guidance is very helpful in explicitly acknowledging that some people, both patients and doctors, regard clinically assisted nutrition and hydration as basic care (while, of course, others regard it as medical treatment). This explicit acknowledgement is a helpful starting point for resolution of disagreements about how to address patient needs.

24. Do you think that there are any other factors that should be included in paragraphs 85-87?

Yes No Not sure **NS**

[Comments]

Some patients may want to request in advance that clinically assisted nutrition and hydration be provided up until the moment they die, because they see these interventions not as medical treatment that can be withdrawn or withheld but as part of basic care. Paragraphs 54-55 of the draft guidance set out general principles about responding to advance requests for treatment and paragraph 93 applies these principles to clinically assisted nutrition and hydration.

25. Are there any specific considerations for responding to requests for clinically assisted nutrition and hydration that are not addressed by the guidance in paragraphs 54-55 or 93?

Yes No Not sure **NS**

Comments

Paragraph 93 seems to take insufficient account of the role of the patient in assessing burdens and benefits in relation to his or her own case. The decision of 'overall benefit' includes these subjective factors and the guidance should make clear that the doctor has expertise in clinical burdens, risks and benefits but not in how these are weighed by the patient. It should be commended in attempting a balance but may need more attention.

Given the importance that many people attach to clinically assisted nutrition and hydration, there are some situations, involving patients who lack capacity to make their own decision, where the public may want additional reassurance that any decision not to start or to continue with clinically assisted nutrition or hydration will be made on a sound basis.

26. Do you agree that paragraphs 90-97 provide clear advice to doctors to enable them to make sound decisions about clinically assisted nutrition and hydration involving patients who lack capacity?

Yes No Not sure

Comments

In general the advice is clear apart from paragraph 94 on 'persistent vegetative state' and paragraph 91 (see response question 27 below). In relation to paragraph 94 it is good that these cases must each go to court and the GMC guidance does not further weaken the law. Clearly, also, the GMC only offers guidance within the law. Nevertheless, the Catholic Church cannot remain silent about the deliberate withdrawal of nutrition and hydration from a patient who needs it and who has not refused it purely on the basis that this patient does not show signs of conscious awareness.

Paragraph 91 addresses situations where a patient's death is not imminent (i.e. expected within hours or days) and where, while clinically assisted nutrition and hydration is likely to prolong their life, the doctor judges that providing it would cause the patient suffering which would be intolerable in all the circumstances. The purpose of this guidance is to ensure that the patient's interests are thoroughly considered prior to any final decision about whether to provide treatment.

We expect that such circumstances might arise in relation to, *for example*, a new born baby with a very poor prognosis who has one or more severe conditions whose treatment involves invasive painful procedures which may be of doubtful overall or benefit.

27. Do you think that the guidance would apply in these circumstances?

Yes No Not sure

Comments

The guidance would apply in the case of a neonate if the imposition of intubation was intolerable in relation to a poor prognosis. This is not far from the case of adults who are dying. Both these cases should be distinguished sharply from patients who are expected to live for a significant length of time and for whom the treatment itself does is not especially burdensome, but who are judged to have a poor quality of life. Clinically assisted nutrition and hydration should never be withdrawn in order to bring to an end a life that is not valued or respected.

The present guidance links the intolerable burden specifically with the treatment and it is important in any change to this paragraph that it is the treatment and not the patient's life that is described as intolerable or futile.

28. Can you suggest any other situations where this guidance would apply?

Yes No Not sure

Comments

It cannot be ruled out that clinically assisted nutrition and hydration might not pose intolerable burdens for some very exceptional adult case, but this must be judged with great care and as in the previous question: specifically in relation to the burdens of the treatment itself.

29. Do you think that the advice in paragraph 91 about seeking a second or expert opinion, is practicable in all healthcare settings?

Yes No Not sure

Comments

This is the minimum necessary in this kind of case.

Cardiopulmonary resuscitation (paragraphs 98-112)

This section of the guidance addresses concerns raised by patients and the public that decisions about future cardiopulmonary resuscitation (CPR) attempts may be made without informing or consulting with the patient and/or the patient's family. It also takes account of other public concerns that patients should not be subject to unnecessary, distressing discussions where their wishes are known or CPR clearly would not work. The guidance aims to achieve a reasonable balance between a) informing and b) consulting patients or those close to them about decisions to attempt, or not attempt, CPR.

30. Do you agree that the guidance in this section achieves this balance?

Yes No Not sure **NS**

[Comments]

Where CPR has only a very small chance of working and a patient wishes CPR to be attempted, the guidance (paragraph 108) asks the doctor to leave a decision about attempting CPR until the time of any cardio-respiratory arrest. In the event that the patient suffers a cardio-respiratory arrest, a decision would be made based on the patient's condition at the time and taking account of the importance they attach to CPR being attempted.

31. Do you agree this is the right approach to dealing with these situations?
Please tell us why you agree or disagree.

Yes No Not sure **NS**

[Comments]

Working in teams

The guidance includes a number of references to the role of teams in making decisions about end of life treatment and care. It recognises that the care patients who are dying receive is often provided by healthcare professionals working in multi-disciplinary teams, and across different healthcare settings, including in the patient's home.

The guidance draws attention to the issues that can arise in relation to teams. These include issues in relation to communication and coordination of care (particularly across service boundaries) as well as the support that teams may need to make complex and often emotionally difficult decisions and to provide support to patients, their families, carers and others close to them.

32. Do you think that there are any important issues about team working in end of life care that are not sufficiently addressed by the guidance?

Yes No Not sure **NS**

[Comments]

General Questions

33. Can you point to any guidance produced by other organisations, or examples of good practice at a local or national level, it might be helpful to flag up in particular sections of the guidance?

Yes No Not sure

Comments

The guidance from the Catholic bishops (*The Mental Capacity Act and 'Living Wills': A practical guide for Catholics*) could helpfully be referenced in paragraph 87 as an example of those who believe that clinically assisted nutrition and hydration is (at least in some circumstances) basic care.

Supporting materials

We plan to develop some additional materials to accompany the guidance. The purpose of these materials is to help to bring the principles of the guidance to life, for example by using case studies or examples of good practice to demonstrate how the guidance might apply in different practical situations or different healthcare settings.

34. Are there any particular issues in the guidance that you would like to see covered in these additional materials?

Yes No Not sure

Comments

For balance it would be good to provide both an example of overtreatment and an example of undertreatment – so that doctors will immediately realise that both represent possible errors.

Impact Assessment

In developing this guidance we have tried to make sure that we have considered the impact of the guidance both on patients and their carers and others close to them as well as the impact on doctors' practice. A partial impact assessment (including an equalities impact assessment) is available [here] and the following three questions ask about the impact of the guidance on practice and care as well as specifically about equalities and human rights impacts

Impact on practice and care

35. Can you identify any ways in which the guidance will impact (either positively or negatively) on doctors' practice or the treatment and care patients receive at the end of life?

Yes No Not sure **NS**

[Comments]

Impact on equalities and human rights

36. Do you think the guidance places sufficient emphasis on the importance of equalities and human rights considerations when making decisions about end of life treatment and care?

Yes **Y** No Not sure

[Comments]

37. Do you think that the guidance will have a different impact (either positive or negative) on particular groups of patients?

Yes **Y** No Not sure

Comments

Clearly it will have a differential impact on those with disability and in particular with mental incapacity, though hopefully this will be a positive impact. It may also impact differently on different religious groups, for example on those whose beliefs about nutrition and hydration are shaped, in part, by religious belief. These could be affected negatively if the guidance as finally agreed does not include the acknowledgement in the draft guidance of 'strong beliefs' about nutrition and hydration.

And finally

34. We would welcome any additional comments you have on the draft guidance. These may include, for example:

- a. anything that is missing from the guidance that you think should be included
- b. areas of duplication or where you think the guidance could be shortened
- c. whether you think the level of detail in the guidance is about right/ too much/too little

Comments

These are very difficult areas and the guidance should not be any shorter than it is nor complex issues over-simplified. Currently the guidance seems to have this about right.

38. Do you have any comments on the consultation documents and/or process to help us improve future GMC consultations?

Yes No Not sure

Comments

The consultation document is very long. Could it not have been simplified by simply asking people to comment on any paragraph in the document that they wished to express a view on (either positively or negatively)?

The requirement to 'log in' online and to input the responses to each question one at a time both provide obstacles to people who wish to participate but are uncomfortable with this technology. It also gives less possibility of people reflecting and revising their answers before they finally submit them.