



15 Morningside Road
Edinburgh EH10 4DP
SCOTLAND, UK

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End of Life Treatment and Care: Good Practice in Decision Making: A Draft Consultation

Consultation response on behalf of the Scottish Council on Human Bioethics:

The **Scottish Council on Human Bioethics** (SCHB) is an independent, non-partisan, non-religious registered Scottish charity composed of doctors, lawyers, biomedical scientists, ethicists and other professionals from disciplines associated with medical ethics.

The principles to which the Scottish Council on Human Bioethics subscribe are set out in the **United Nations Universal Declaration of Human Rights** which was adopted and proclaimed by the UN General Assembly resolution 217A (III) on the 10th of December 1948.

The SCHB is very grateful to the General Medical Council for this opportunity to respond to the consultation entitled **End of Life Treatment and Care Good Practice in Decision Making**. It welcomes the General Medical Council's intention to promote public consultation, understanding and discussion on this topic.

Not all questions will be responded to.

Scottish Council on Human Bioethics Response:

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?

Scottish Council on Human Bioethics Response:

Paragraph 9, first sentence: This indicates that:

“Good end of life care helps patients with life-limiting conditions to live as well as possible until they die, and to die with dignity.”

However, since (1) human dignity can never be lost nor diminished and (2) it is not always possible to determine ‘end of life’, it would be preferable if this sentence read;

“Good palliative care helps patients with life-limiting conditions to live as well as possible until they die, and to die with their dignity being respected.”

This is in accordance with the United Nations’ Universal Declaration of Human Rights which affirms in its preamble “the inherent dignity and...the equal and inalienable rights of all members of the human family” as “the foundation of freedom, justice and peace in the world”.

Paragraph 11:

The SCHB does not understand why the term ‘artificial nutrition and hydration’ was replaced with ‘clinically assisted nutrition and hydration’ which it finds misleading and inappropriate. Further comments on this issue are presented under the reply to Question 21.

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 are other general problems or issues in relation to equality, diversity and human rights that we should flag up in this section?

Scottish Council on Human Bioethics Response:

The GMC should respect the following international Conventions:

- United Nations Convention on the Rights of Persons with Disabilities¹ (legally binding). Entered into force on 3 May 2008 (the UK has signed (30 March 2007) but not ratified this Convention). The following article states that:

Article 25 - Health

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

(f) Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.

- Council of Europe Convention on Human Rights and Biomedicine, ETS - No. 164² (legally binding). Entered into force on 1 December 1999 (the UK has not signed nor ratified this instrument). The following article states that:

Article 5 – General rule

An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.

This person shall beforehand be given appropriate information as to the purpose and nature of the intervention as well as on its consequences and risks.

The person concerned may freely withdraw consent at any time.

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 36-42). 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 36-42 of the draft guidance.

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

¹ UN Convention on the Rights of Persons with Disabilities, Entered into force on 3 May 2008, The UK has signed but not ratified this Convention, <http://www.un.org/disabilities/default.asp?id=259>

² Convention on Human Rights and Biomedicine, ETS No.164, <http://conventions.coe.int/Treaty/en/Treaties/Word/164.doc>

Scottish Council on Human Bioethics Response:

The SCHB agrees that decisions concerning life-prolonging treatment 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.

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.

Scottish Council on Human Bioethics Response:

The SCHB recognises that it is sometimes difficult to diagnose how long a patient has to live. In addition, some doctors may think of palliative care as something that is only relevant to the last days of life.

In this respect, the SCHB believes that the guidance will help doctors think about the likely progression of a patient's condition and the need to plan for palliative care.

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?

Scottish Council on Human Bioethics Response:

The SCHB believes that the guidance is appropriate to ensure that patients' needs for symptom management and pain relief will be met adequately.

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?

Scottish Council on Human Bioethics Response:

The SCHB is of the opinion that the guidance will lead to more patients, family members and carers receiving the support they want and need.

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?

Scottish Council on Human Bioethics Response:

The SCHB agrees that these sections include sufficient advice about good communication and means of supporting patients, those close to them and members of the healthcare team.

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 are covered by other guidance³.

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.

Assessing the overall benefits of treatment options (paragraphs 36-42)

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 36-42 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 stop or not to start a potentially life-prolonging treatment?

Scottish Council on Human Bioethics Response:

The SCHB notes that the following, or similar, definitions are applied in the UK:

Benefit: *The clinical advantage or the net gain that a person may receive through a particular intervention.*

Since the Tony Bland case (1993) in England and Wales, benefit has included non-clinical benefit and may encompass the very existence of a person (being alive).

Best interests: *The highest level of well-being that is achievable for a specific person. Best interests include medical benefit, respect for the wishes and beliefs of the patient including his or her spiritual and religious beliefs.*

Whether artificial nutrition and hydration constitutes medical treatment or basic care was one of the central questions considered by the UK House of Lords in the Bland case⁴. The view of three of the five Law Lords who considered this case was expressed by Lord Goff as follows⁵:

"There is overwhelming evidence that, in the medical profession, artificial feeding is regarded as a form of medical treatment; and even if it is not strictly medical treatment, it must form part of the medical care of the patient".

This classification of artificial nutrition and hydration as medical treatment, though not generally accepted, has however been adopted in other subsequent cases in England and Wales⁶ and is now

³ *Good Medical Practice: Responsibilities of doctors in a national pandemic* (2009)
http://www.gmc-uk.org/guidance/news_consultation/medical_pandemic.asp

⁴ *Airedale NHS Trust v Bland* [1993].

⁵ *Airedale NHS Trust v Bland* [1993] 1 All ER 821.

⁶ See, for example, *Frenchay Healthcare NHS Trust v S* [1994] 1 WLR 601, *Re D (Medical Treatment)*[1998] 1 FLR 411.

established common law. Moreover, artificial nutrition and hydration can now be withdrawn from mentally incapable patients if physicians deem it to be in their best interest.

In the light of this, the SCHB disagrees with the manner in which benefit is defined in UK Case Law when it is understood in the context of the deceased and especially after the Tony Bland case. Indeed, the Oxford English Reference Dictionary⁷ indicates that the noun 'benefit' is defined as a "favourable or helpful factor or circumstance".

However, being dead cannot be considered in any philosophical, rational or logical manner as a favourable or helpful factor or circumstance since death represents the ending of the existence of the person from a medical or legal perspective. Thus, from a rational and logical perspective, a "favourable or helpful factor or circumstance" cannot exist when the subject to which it refers does not exist.

Therefore, from a medical or legal perspective, the concept of benefit cannot apply to a deceased person.

Moreover in para. 2.62 of the 2002 version of the Code of Practice of the Adults with Incapacity (Scotland) Act 2000 it is indicated that:

"Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult."

Accordingly, the SCHB believes that the use of words such as 'benefit' and 'best interest' in end of life contexts, such as the one considered in the Tony Bland case, is mistaken. Indeed, though it may be appropriate, in certain circumstances, to let a patient die from natural causes, consciously ending the life of a person cannot be in his or her 'benefit' or 'best interest'.

Furthermore, the SCHB is deeply concerned by the proposal that some lives may be better terminated by another person than left to continue to live. This would mean that society agrees (for the first time) that some lives, for whatever reason, are no longer worth living and have lost all their value or meaning and should be brought to an end.

Indeed, there is a real danger that these lives may be portrayed in a similar manner to those presented in the first half of the century as "Lebensunwertes Leben" (life unworthy of life) in Germany.

Moreover, supporting such a concept means that it is acceptable to help kill those whom society believes have a meaningless and worthless life.

This, would have a brutalising effect on society and dangerously undermine the legal protection established in the concept of human dignity. A concept characterised by international, globally accepted, legal texts such as the United Nations' Universal Declaration of Human Rights (1948). Indeed this Declaration affirms in its preamble "the inherent dignity and...the equal and inalienable rights of all members of the human family" as "the foundation of freedom, justice and peace in the world".

Such texts emphasise the important universal and absolute nature of the concept of human dignity. In other words, they support the notion that no person (including oneself) can lose his or her human dignity at any time in his or her life.

Finally, the SCHB concurs that it would be ethically wrong to withhold or withdraw medical treatments, nutrition or hydration, howsoever administered, from any person who does not have the capacity to make a decision with the intention of causing the death of, or causing harm to, that person.

Advance care planning (paragraphs 43-53)

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 43-53 include all of the key issues that are relevant to advance care planning? If not, please tell us what other issues should be included.

⁷ The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

Scottish Council on Human Bioethics Response:

The SCHB concurs that:

- **Badly expressed advance directives may mislead or cause confusion and result in patients being treated differently from the manner in which they intended or not at all.**
- **Advance directives may not correspond to a real situation since the diagnosis and prognosis of a specific disease are always open to uncertainties and even mistakes.**
- **Advance directives may sometimes reduce rather than enhance the opportunities for discussion. Inhibitions about raising the matter with health professionals may indeed lead some persons to draft them in isolation.**

Acting on advance requests for and refusals of treatment (paragraphs 54-61)

In answering these questions, please see the sections in the draft guidance on clinically assisted nutrition and hydration (paragraphs 83-97) and cardiopulmonary resuscitation (paragraphs 98-112), to see how the principles in paragraphs 54-55 are applied in practice in relation to these specific treatments

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 of 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 benefit 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?*

Scottish Council on Human Bioethics Response:

The SCHB agrees 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.

In this regard, the SCHB agrees that decisions concerning life-prolonging treatment 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.

Further comments on the possibility of replacing 'artificial nutrition and hydration' with 'clinically assisted nutrition and hydration' are presented under the reply to Question 21.

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?*

Paragraphs 56-61 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?*

Scottish Council on Human Bioethics Response:

Guidance on advance requests for and refusal of treatment should be separated in the document.

There should also be a possibility for the person to review an Advanced Directive where appropriate.

Moreover, the Adults with Incapacity (Scotland) Act 2000 and its Code of Practice regulate advance directives in Scotland.

A summary of the different issues are below:

1. Advance Decisions (General):

In para. 2.62 of the 2002 version of the Code of Practice it is indicated that:

“Nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient... ... the Act does not permit any form of euthanasia, which remains a criminal act under Scots Law.

Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law...

All interventions under the Act (including some omissions to act) must comply with the general principles that all interventions must benefit the adult, and that any intervention must be the least restrictive option in relation to the freedom of the adult. Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult.

Section 47 of the Act only allows intervention to “safeguard or promote the physical or mental health of the adult”. This does not impose a duty to provide futile treatment or treatment where the burden to the patient outweighs the clinical benefit.”

2. Advance (written) Statements

Advance (written) statements are not specifically covered by the Adults with Incapacity (Scotland) Act 2000. But since there has been common law in England that suggests⁸ that persons may refuse, in advance, undesired procedures if they become incapacitated, a body of opinion believes that the courts in Scotland would not take a different approach. However, a clear position does not exist.

Paragraph 2.29 of the 2002 version of the Code of Practice of the Adults with Incapacity (Scotland) Act 2000 states that:

“A competently made advance statement made orally or in writing to a medical practitioner, solicitor or other professional person would be a strong indication of a patient’s past wishes about medical treatment but should not be viewed in isolation from the surrounding circumstances. The status of an advance statement should be judged in the light of the age of the statement, its relevance to the patient’s current healthcare needs, medical progress since the time it was made which might affect the patient’s attitude, and the patient’s current wishes and feelings. An advance statement cannot bind a medical practitioner to do anything illegal or unethical. An advance [statement] directive is a document which specifically refuses particular treatments or categories of treatment. Such documents are potentially binding. When the medical practitioner contemplates overriding such a directive, appropriate guidance should be sought.”⁹

3. Enduring Powers of Attorney

The Adults with Incapacity (Scotland) Act 2000 allows the appointment of a proxy decision maker (a guardian, welfare attorney or person authorised under an intervention order) who is entitled to give

⁸ No agreement has yet been reached in England concerning the full extent of case law relating to the legally binding nature of advance statements.

⁹ Paragraph 2.29 of the 2002 version of the Code of Practice relating to the Adults with Incapacity (Scotland) Act 2000. <http://www.scotland.gov.uk/health/cmo/mcpasprint.pdf>

consent to the medical treatment of an incapacitated patient over the age of 16. Where such a proxy is appointed, he or she must be consulted (where reasonable and practicable) about a proposed medical treatment.

The authority of a proxy to refuse treatment on behalf of an incompetent patient would, it is thought, depend largely on whether the refusal conformed with the patient's own wishes and whether those could be shown to be informed and applicable.

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 multiagency 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 62-65 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?

Scottish Council on Human Bioethics Response:

The SCHB believes that, in the context of persons who are dying, it is important that there is good communication between healthcare professionals and that lines of accountability and responsibility are clear.

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 42 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?

Scottish Council on Human Bioethics Response:

Conscientious objections often arise when intention is being considered since allowing terminally ill patients to die when there is nothing more that can be done to relieve their symptoms or treat their illness has long been part of good medical practice. On the other hand, letting patients die when useful symptom-relief or treatment can be given is negligent.

Thus, under the Principle of Double Effect the provision of drugs to address physical suffering is deemed ethically acceptable even if these may shorten the life of the dying patient. This is because the doctor's intended outcome is pain relief and the unfavourable result of shortening life is not the intent.

However, the SCHB agrees that there may be some rare circumstances 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.

In this case, if a physician objects to a patient's decision to refuse life-prolonging treatment or to a decision that such treatment will not be of overall benefit to a patient who lacks capacity to decide because of his or her personal beliefs, he or she may withdraw from the patient's care.

However, this must not be undertaken without first ensuring that arrangements have been made for another doctor to take over his or her role. It would not be acceptable to withdraw from a patient's care if this would leave the patient, or colleagues with nowhere to turn¹⁰.

¹⁰ Refer to the GMC guidance 'Personal Beliefs and Medical Practice' (2008).

Moreover, the SCHB is also of the view that it would not be acceptable for healthcare trusts to avoid their duty and responsibility to ensure that conflicts relating to conscientious objections are only extremely exceptional and are documented in writing. In addition, if conflicts do take place, trusts must ensure that measures are taken in order to avoid such conflicts in the future without putting pressure on the physician to resign or change his or her post in the healthcare service.

In general, it is very rare for a patient to refuse hydration and nutrition. But if a patient with capacity refuses hydration and nutrition with a clear suicidal intention, many physicians would find this difficult to support. It would therefore be for the doctor to exercise his or her right of conscientious objection.

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

Scottish Council on Human Bioethics Response:

The SCHB notes that many physicians with conscientious objections are already finding it difficult to practise in certain medical specialities. This is a very unfortunate development and must be addressed by healthcare trusts. For example, trusts should provide appropriate solutions and alternatives which support the physicians in their practice without putting pressure on them to leave or change their area of medical expertise.

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?

Scottish Council on Human Bioethics Response:

The SCHB agrees that this section gives sufficient detail about the key issues that need to be considered after a patient's death.

The body should always be treated with respect and not just when relatives or friends are present. The body should be covered at all times and not completely naked. When an intervention is required in a certain area of the body, other areas should remain covered.

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?

Scottish Council on Human Bioethics Response:

The SCHB concurs that 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.

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?

Scottish Council on Human Bioethics Response:

The SCHB believes that such a separation of roles should always be sought even though this may sometimes prove difficult.

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 young people, and especially premature babies. The guidance builds on the advice in *0-18 years: guidance for all doctors (2007)*, 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?

Scottish Council on Human Bioethics Response:

The SCHB is concerned that palliative care may sometimes be given to infants who are disabled but who are not dying. In this case, the decision has been made on the basis of 'value of life' which healthcare professionals are not qualified to make.

Clinically assisted nutrition and hydration (paragraphs 83-97)

Paragraphs 83-97 of the guidance give advice to doctors on meeting patient's needs for nutrition and/or hydration, including by clinically assisted means, for example, through a drip, nasogastric tube or through a 'PEG' or 'RIG' feeding tube through the abdominal wall. It includes advice on assessing needs, providing support for patients to take food and drink orally as well as decisions about whether to provide or withdraw nutrition or hydration provided by clinically assisted means.

There are 9 questions about this section of the guidance.

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?

Scottish Council on Human Bioethics Response:

1. Nutrition and Hydration is a form of Basic Care

The benefit of receiving nutrition and hydration are the essential elements required to stay alive and can be considered as a form of basic care. Thus, nutrition and hydration should be given to all patients, except if the patient is conscious and refuses or if it is futile and the patient is in the last stages of a terminal illness in which case the intention is to relieve suffering rather than to hasten death.

2. What does 'clinical' mean?

The SCHB notes that a clear definition for "clinically assisted nutrition and hydration" is not given in the proposed GMC guidelines. Instead, just a number of examples are included to characterises this term in paragraph 85. This is unfortunate and makes it difficult to support any appropriate discussion on the relevant issues.

The Oxford English Reference Dictionary indicates that the adjective 'clinical' relates to the treatment of a patient¹¹.

¹¹ The Oxford English Reference Dictionary, Second Edition, Edited by Judy Pearsall and Bill Trumble, Oxford University Press, 1996.

In this regard, a treatment can vary in its complexity from something requiring extensive technological experience to a procedure which can be applied by any person in society. For example, a treatment can now sometimes be provided by a person himself or herself which, in the past, could only be provided by a physician or a nurse.

In other words, the term ‘treatment’ is not defined by the person who applies it. I.e. a ‘clinical treatment’ does not always need to be applied by a clinician.

Instead, it reflects the reality that an individual may require assistance and support from a drug or application in addition to what is naturally provided by his or her body.

In this regard, the SCHB notes that oral nutrition is sometimes poorly provided. Thus if ‘clinically assisted’ means being fed by a skilled nurse, there is then a risk of extending the uncertainties of the expression to a part of oral feeding. A risk would then exist that only those who can feed themselves are entitled to nutrition.

The decision to provide enteral nutrition using either a naso-gastric or gastrostomy (PEG or RIG) tube can be difficult and should be individualised with respect to balancing the benefits versus the burdens. In other words, the decision when and whether to begin needs to be considered very carefully.

In this regard, the insertion, as such, of a hydration and nutrition apparatus may be seen as ‘clinical’ since it involves a minor surgical procedure which, although now routine, can have complications and requires consent from the patient when this is possible.

The insertion of the tube is done by a person trained in the technique and on-going support is needed from other health care professional’s such as a specialist nutrition nurse and/or dietician¹².

3. Difficulties with respect to the terminology

The SCHB notes that the classification of artificial nutrition and hydration as a medical treatment was adopted in Scotland in 1996 through the case of the Law Hospital NHS Trust v Lord Advocate¹³ and has been established in case law.

However, when the 2002 version of the Code of Practice of the Adults with Incapacity (Scotland) Act 2000 was prepared it was indicated in para. 2.62 that:

“Nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient...

... Any health professional, like any individual, who acted by any means¹⁴ – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law.”

Thus, since nutrition and hydration can be regarded as a form of basic care which should always be provided unless it is futile and the patient is dying and since the insertion of an application to provide this nutrition and hydration may be regarded as a clinical treatment which may be refused in certain circumstances, a tension or difficulty arises in characterising the overall terminology to describe the provision of nutrition and hydration when the patient cannot be fed or hydrated through the mouth.

Because of this, and since it would be ethically wrong to consider the provision of hydration and nutrition to a person who has lost incapacity and who is not dying as just a “clinical treatment” which can be refused in certain circumstances, the SCHB believes that the expression “clinically assisted nutrition and hydration” is inappropriate and misguided.

It is concerned that by using such terminology, the GMC may inadvertently restrict or misrepresent a situation which requires more flexibility in its understanding in order to provided the appropriate care for, and protection to, a patient.

¹² Clinical trials have shown that in certain conditions , such as advanced dementia , gastrostomy feeding did not reduce morbidity or mortality.

¹³ Law Hospital NHS Trust v Lord Advocate, (1996) SLT 848.

¹⁴ Note: “Any means” includes all interventions whether or not they are clinical and/or whether or not they are treatments.

In this regard, it should be noted that a number of European countries would not officially recognise assisted nutrition and hydration as a medical treatment.

For example, the Italian Senate passed a bill by 150-123 on the 26th of March 2009 which indicated that while patients have a right to refuse treatment, they cannot refuse nutrition or hydration because these are not considered as being treatments but "vital support."¹⁵

Moreover, international law does not indicate that assisted hydration and nutrition should be considered as a treatment.

The GMC Guidance document also recognises this in paragraph 51 when it states that: "Some patients may hold strong views about receiving clinically assisted nutrition and hydration towards the end of their life, because they see these not as medical treatment but part of basic care."

Thus, the SCHB would prefer the term 'assisted nutrition and hydration' (as used in question 26 of the GMC consultation) to be employed on its own which does not restrict the definition of the procedure and provides the possibility to look after the patient in an appropriate manner. Alternatively, as with the 2006 NICE guidelines, the term "supported nutrition (and hydration)" could be used.

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?*

Scottish Council on Human Bioethics Response:

The SCHB is of the view that 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.

Notes:

The SCHB is very concerned about the experience of two women, in 2008-2009, who consulted Friends At The End (FATE) in Scotland for advice to end their lives through starvation and dehydration whilst refusing palliative care¹⁶.

One woman, an 85-year-old retired teacher from Middlesex, was terminally ill but her requests for a lethal dose of barbiturates were refused by her doctors. She was told she would have to wait for a month for an appointment in a Swiss euthanasia clinic so began refusing food and drink in January 2009. It took her five agonising days to die. Her daughter indicated "Her body mass reduced, her face became drawn, her skin very dry. She was dying of thirst. It was like being in the desert. I feel my mother was tortured until she died."

In addition, a 75-year-old from Scotland, who had advanced motor neurone disease, took 25 days to starve and dehydrate to death after consulting FATE for advice. As the days turned into weeks, she used a communication aid to write: "You wouldn't put a dog through this. You would give it a lethal injection." Dr Wilson from FATE, who was in contact with the woman said her agony had been prolonged by her sucking ice cubes and frequently rinsing her mouth with water.

Relatives of both women indicated that their deaths were horrific.

¹⁵ Italian Senate approves end-of-life bill that bans withdrawing food and water from patients, Associated Press, 26 March 2009, Star Tribune, http://www.startribune.com/world/41923667.html?elr=KArks:DCiUBcy7hUiD3aPc:_Yyc:aUU

¹⁶ Simon Johnson, Retired GPs advise terminally ill on suicide by starvation, 8 March 2009, The Telegraph, <http://www.telegraph.co.uk/health/healthnews/4957436/Retired-GPs-advise-terminally-ill-on-suicide-by-starvation.html>

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?

Scottish Council on Human Bioethics Response:

The SCHB agrees that setting out these complicating factors is helpful. Indeed, it is not a minority of people that consider the provision of assisted hydration and nutrition as part of basic medical care. Indeed, a number of European countries would not officially recognise assisted nutrition and hydration as medical treatment.

For example, the Bill passed by the Italian Senate mentioned above indicated that while patients have a right to refuse treatment, they cannot refuse nutrition or hydration because these are not considered as being treatments but "vital support."¹⁷

Moreover, international law does not indicate that assisted hydration and nutrition should be considered as a treatment.

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

Scottish Council on Human Bioethics Response:

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?

Scottish Council on Human Bioethics Response:

The SCHB agrees that, where a patient's death is imminent (expected within hours of days) and assisted nutrition and hydration are already in use but are considered to be futile, it usually will be appropriate to stop the nutrition and hydration.

In this regard, the SCHB acknowledges that it can be very difficult to judge how long a patient has to live. In a recent study from a hospice in Manchester, no group of health care professionals got its prognosis right more than 50% of the time¹⁸. In addition, it has been suggested that there was sometimes a misjudgement by a matter of months¹⁹. Thus physicians must always be prepared to re-appraise their prognosis.

But even though prognostication is difficult, when patients approach the last days/weeks of life then it is generally recognised as being easier (though some doctors struggle to say their patient is ever dying as they regard labelling someone as dying is a failure).

¹⁷ Italian Senate approves end-of-life bill that bans withdrawing food and water from patients, Associated Press, 26 March 2009, Star Tribune, http://www.startribune.com/world/41923667.html?elr=KArks:DCiUBcy7hUiD3aPc:_Yyc:aUU

¹⁸ Feargal Twomey, O'Leary N, O'Brien T. Prediction of patient survival by healthcare professionals in a specialist palliative care inpatient unit: a prospective study. American Journal of Hospice Care, Vol 25 No 2. April/May 2008, p139-145. DOI:10.1177/1049909107312594

¹⁹ Dr. Gillian Craig, consultant geriatrician, Innovative approaches and ethical issues associated with end of life care, 9th December 2008, Westminster Health Forum papers.

Moreover, if a patient had previously requested that nutrition and hydration be continued until their death, physicians should take this into account in deciding what course of action would be in the patient's overall interests, having regard to the harm that might be caused, on the one hand by going against the patient's wishes and on the other, by continuing to provide assisted nutrition or hydration.

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?

Scottish Council on Human Bioethics Response:

The SCHB does not believe that paragraphs 90-97 provide clear advice to physicians in Scotland to enable them to make sound decisions about assisted nutrition and hydration involving patients who lack capacity.

For Scotland, the SCHB would prefer the words from para. 2.62 of the 2002 version of Code of Practice of the Adults with Incapacity (Scotland) Act 2000 to be used instead. In other words, that:

“Nothing in the Act authorises acts or omissions which harm, or are intended to bring about or hasten the death of a patient... .. the Act does not permit any form of euthanasia, which remains a criminal act under Scots Law...

Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law...

All interventions under the Act (including some omissions to act) must comply with the general principles that all interventions must benefit the adult, and that any intervention must be the least restrictive option in relation to the freedom of the adult. Clearly, an intervention under Part 5 of the Act which adversely affects the well-being of an adult or causes harm or even death to that adult cannot be described as bringing a benefit to that adult.

Section 47 of the Act only allows intervention to “safeguard or promote the physical or mental health of the adult”. This does not impose a duty to provide futile treatment or treatment where the burden to the patient outweighs the clinical benefit.”

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 benefit.

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

Scottish Council on Human Bioethics Response:

The SCHB disagrees that assisted nutrition and hydration should be withheld or withdrawn from patients who are not dying. Indeed, having a poor prognosis is very different to a situation where the patient is dying.

The SCHB recognises that some treatments may involve painful procedures which may be of doubtful overall benefit. But for a healthcare professional to withdraw or withhold nutrition and

hydration with the aim of bringing about death when the patient is not dying is equivalent to euthanasia and will be liable to prosecution in Scotland.

In law, there is a very basic and important distinction between letting nature take its course and being responsible for the death of a person.

Moreover, it is not the length of a life (whether short or long) that gives this life dignity. In other words, all human life deserves the same respect, care and protection.

In addition, for a healthcare professional to be explicitly responsible for the death of another person may have very serious consequences (both short and long-term) on his or her overall psychological balance. It may even have a brutalising effect on the healthcare professional who is implicated in such a procedure.

The interpretation of the benefit burden balance ratio and the judgement of when someone is dying may be varied and lead to differences of implementation of the guidelines. Maybe more detailed guidelines are needed.

Finally, the SCHB questions whether it would be possible to measure “the suffering which would be intolerable” in patients without capacity. It also questions whether healthcare professionals can determine this on behalf of the patient.

Indeed, the SCHB notes that there is a fundamental difference between making health care decisions and making value-of-life decisions. Physicians are not qualified to make value-of-life decisions or to decide which life is worthwhile and which is not. Physicians may determine whether an intervention in the health field is futile and valueless, but they can never determine whether a life is futile or valueless.

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

Scottish Council on Human Bioethics Response:

The SCHB believes that the guidance in paragraph 91 is misleading and could potentially lead to the prosecution of physicians in Scotland.

As indicated in para. 2.62 of the 2002 version of the Code of Practice of the Adults with Incapacity (Scotland) Act 2000:

“Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law.”

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

Scottish Council on Human Bioethics Response:

The SCHB believes that the guidance in paragraph 91 is misleading and could potentially lead to the prosecution of physicians in Scotland.

As indicated in para. 2.62 of the 2002 version of the Code of Practice of the Adults with Incapacity (Scotland) Act 2000:

“Any health professional, like any individual, who acted by any means – whether by withholding treatment or by denying basic care, such as food and drink – with euthanasia as the objective, would be open to prosecution under the criminal law.”

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?

Scottish Council on Human Bioethics Response:

The SCHB agrees that the guidance in this section achieves a reasonable balance between (a) informing and (b) consulting patients or those close to them about decisions to attempt, or not attempt, CPR.

The SCHB also recognises that it is important for healthcare professionals to record any discussions with patients and relatives about CPR.

The information provided in these discussions should also be pitched to the appropriate needs and requirements of the patient.

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.

Scottish Council on Human Bioethics Response:

The SCHB agrees that this is the right approach to dealing with these situations. The wishes of the patient for CPR to be attempted should indeed be balanced with the physician's experience relating to the possible futility of such an action.

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 for patients who are dying is often provided by healthcare professionals working in multidisciplinary 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?

General Questions

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

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?

Scottish Council on Human Bioethics Response:

Further directives and guidance may be appropriate for crime and accidents scenes.

Impact on services and standards of care

In further developing this guidance we want to know about any changes that doctors, or the organisations in which they work, might have to make to their existing practice or arrangements for providing healthcare services to patients (and those close to them) in order to meet the standards set out in the guidance.

We also want to assess any ways in which the guidance would impact specifically on the quality of care experienced by particular patients or groups of patients (and those close to them).

The following three questions are intended to gather evidence on these points.

Impact on existing practice

35. *Can you identify any changes that would be needed in order to meet the standards set out in the guidance? (For example in service organisation or delivery, or in the resources needed to provide treatment and care to patients towards the end of life).*

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?*

37. *Do you think that the guidance will have a different impact - either positive or negative - on particular groups of patients? (For example, on the basis of a person's age, colour, culture, disability, ethnic or national origin, gender, lifestyle, marital or parental status, race, religion or beliefs, sex, sexual orientation, or social or economic status)*

And finally

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

c. anything that is missing from the guidance that you think should be included

d. areas of duplication or where you think the guidance could be shortened

e. whether you think the level of detail in the guidance is about right/ too much/too little

Scottish Council on Human Bioethics Response:

It would be appropriate for the GMC to draft guidelines which reflect the specific Scottish legislation.

Advance Directives:

Advance directives have been increasingly considered as a response to the demand by patients for a greater amount of autonomy and control concerning decisions and responsibilities with respect to their health. This has arisen in an environment in which a growing lack of familiarity or even mutual trust may exist between patients and the providers of health care.

The SCHB recognises that competent patients are entitled to make their own decisions concerning medical interventions in order to, for example, avoid breaching their personal or religious beliefs. However, autonomy is not a simple issue, especially when another person's autonomy, rights and views are present.

Moreover, even if only a few days old, advance directives may not reflect the patient's contemporaneous wishes. People's attitudes and wishes often change with the onset of a serious disease, with time and with other personal circumstances. In addition, new medical developments may mean that novel forms of treatment may exist which were not foreseen when the advance directives were prepared.

Furthermore, it may be difficult to establish retrospectively whether a person had capacity at the time of making an advance directive. It is also unclear what level of capacity is required in order to revoke a directive, once made.

Thus, because advance directives may not always reflect the real wishes or the specific situation of a patient when a medical decision is being envisaged, the SCHB considers that they should not be legally binding. This gives those caring for incapacitated persons essential flexibility in the provision of appropriate care and treatment.

Value-of-life decisions:

The SCHB notes that there is a fundamental difference between making health care decisions and making value-of-life decisions. Physicians are not qualified to make value-of-life decisions or to decide which life is worthwhile and which is not. Physicians may determine whether or not an intervention in the health field is futile and valueless, but they can never determine whether a life is futile or valueless.

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

Thank you for taking the time to send us your comments – we are grateful for your input.