

**CHRISTIAN CONCERN FOR OUR NATION &
THE CHRISTIAN LEGAL CENTRE
RESPONSE TO THE CONSULTATION ON
NEW DRAFT GUIDANCE FOR DOCTORS
“END OF LIFE TREATMENT AND CARE:
GOOD PRACTICE IN DECISION-MAKING”
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The Consultation can be found here:

http://www.gmc-uk.org/guidance/news_consultation/eol_care.asp.

About Us

Christian Concern for Our Nation (CCFON) is a policy and legal resource centre that identifies changes in policy and law that may affect the Judeo-Christian heritage of this nation. The team of lawyers and advisors at CCFON conduct research into, and campaign on, legislation and policy changes that may affect Christian Freedoms or the moral values of the UK. CCFON serves a mailing list of 25,000 supporters. <http://www.ccfon.org>

CCFON is linked to a sister and separate organisation, the Christian Legal Centre, which takes up cases affecting Christian freedoms. <http://www.christianlegalcentre.com>

Response to the General Medical Council Consultation

Our response seeks to address the principles that stem from the General Medical Council's consultation: "End of Life treatment and care: Good practice in decision-making".

As an organisation, we believe in the value of life as given by God and as such are concerned about the practices that affect life during the critical stages of medical treatment.

The public was invited to respond to a thirty-nine questions in the consultation and therefore this response will use these questions loosely as a guideline.

The Authorities' Consultation

The General Medical Council (GMC) is to be commended for presenting this consultation and inviting the public to respond to it. The issues that they address affect everyone and as such their willingness to engage the public in dialogue does not go unnoticed.

Equalities and Human Rights

We believe that every person, regardless of ethnicity, race or age, has value and as such should have an equal opportunity to experience the best level of health care available to them. Every person should have equal opportunity to know what their medical options are and what support can be provided to them. This need is heightened in the gravest of circumstances especially during end of life treatment.

We do not 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.

It must be remembered that the right to life is paramount; it is the gateway to all other rights and freedoms. Placing undue emphasis on the idea of "quality of life" and on treatment being "intolerable" leads to the right to life being undermined.

Article 3 of the United Nations' Universal Declaration of Human Rights 1948 enshrines the right to life, as does article 6 of the International Covenant on Civil and Political Rights 1966, making it a legally enforceable right in every member of the United Nations:

"Every human being has the inherent right to life. This right shall be protected by law. No one shall be arbitrarily deprived of his life."—Article 6.1 of the International Covenant on Civil and Political Rights, see: http://en.wikipedia.org/wiki/Right_to_life.

Presumption in Favour of Prolonging Life

There is a worrying trend in our secular society today that tends to devalue life. Evidenced through moves to end it, there have been strides to encourage and legalise assisted suicide where relatives help a person to travel abroad in order to commit suicide. Thankfully, the proposed amendment to the Coroners and Justice Bill that was debated on 7th July and that sought to legalise assisted suicide in such circumstances as a first step on the slippery slope to euthanasia was not accepted. We welcome the BMA's recent decision at its annual representative meeting in Liverpool overwhelmingly to oppose legalising assisted suicide and to stand with the RCP, the RCGP, the RCN and the two thirds of doctors who consistently say in all opinion polls that they do not wish the law to change.

We support the GMC's view on the need to prolong life and functioning from a place of presumption in favour of it. Where the consultation is unclear is on how long there will be encouragement to prolong life. We believe that life has value and we therefore support the medical profession in their endeavour to encourage individuals to prolong their lives. We challenge the GMC to ensure that doctors exhaust as many options as possible and that the guidance will make this clear.

In particular, within point 18 on page 10, we consider it important to stress section 4(5) of the Mental Capacity Act 2005, which sets down the principle that where a determination relating to life-sustaining treatment is being made for a patient who lacks capacity, the person making the decision:

...must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

We believe that in order to support the principle of prolonging life, the proviso at the end of the last sentence of point 112 regarding emergencies and CPR should be removed. The sentence should end with "In these circumstances, CPR should be attempted" and remove "unless you are certain you have sufficient information about the patient to judge that it will not be successful."

To support the presumption in favour of prolonging life regarding advance decisions, in accordance with section 25 of the Mental Capacity Act 2005, it is vitally important that the guidance should stress the need for a doctor to be absolutely sure that such decisions at the material time are both valid and

applicable to the treatment and to stress the circumstances in which they are not valid or are not applicable.

There has been much discussion in the national media in such publications as *The Daily Telegraph* and *The Independent* regarding the need for patients to have ample support and to be cared for when making these decisions.

Advance Decisions

A patient's advance wishes to receive treatment should be respected and going against them should be treated as a potential harm. The focus, of course, should be on meeting the patient's needs for palliative care, including effective symptom management and adequate pain relief. There is a danger that ignoring a patient's advance wishes to receive treatment could result in decision-making based upon what is convenient resource-wise for the hospital, as opposed to the patient's wishes and best interests.

In our opinion the withdrawal of clinically assisted nutrition or hydration against the patient's wishes is definitely a harm and does not respect pro-life and religious views on the sanctity of life, nor views that oppose euthanasia.

It is particularly important to ensure that there is adequate palliative care provided at home. Research commissioned by Marie Curie Cancer Care shows that 64 per cent of people would choose to die at home. In reality only 25 per cent achieve this. (See: [http://www.mariecurie.org.uk/whatwedo/?WT.srch=I\(paid\)&gclid=Clrb7bbn0psCFU0B4wodDkLdJA](http://www.mariecurie.org.uk/whatwedo/?WT.srch=I(paid)&gclid=Clrb7bbn0psCFU0B4wodDkLdJA))

"Palliative care is part of supportive care. It embraces many elements of supportive care. It has been defined by NICE as follows:

Palliative care is the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments. See: http://www.ncpc.org.uk/palliative_care.html).

It is vitally important in the home setting to ensure that section 4(5) of the Mental Capacity Act 2005, which sets down the principle that where a determination relating to life-sustaining treatment is being made for a patient who lacks capacity, is respected, so that the person making the decision:

...must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

It is important that the doctor, in acting in the best interests of the patient (not only where they lack capacity, but also when they have capacity) ensures that such decisions are never determined by a desire to bring about death. The desire for death either by the patient or a caring relative may be motivated simply by the patient's depression resulting from a lack of palliative care and a feeling of no

longer being able to cope. The doctor should make every effort to contact all available sources of help to provide end of life treatment and care, so as to respect the presumption in favour of prolonging life. The draft guidance fails to address this particular issue.

The guidance does not make clear, in our view, how doctors should decide whether a patient's advance refusal of treatment should be acted on. It is important to support the presumption in favour of prolonging life regarding advance decisions, in accordance with section 25 of the Mental Capacity Act 2005. It is vitally important that the guidance should stress the need for a doctor to be absolutely sure that such decisions at the material time are both valid and applicable to the treatment and to stress the circumstances in which they are not valid or are not applicable.

Paragraphs 58 to 61 do not emphasise this point sufficiently. In addition, although (as stated in paragraph 61) it is necessary to consult those caring for the patient, particularly if they have any legal authority, such consultation is not part of the criteria for the decision-making in section 25 of the Mental Capacity Act. Instead, section 25 is based on whether or not the advance refusal of treatment is both valid and applicable. There seems to be too much emphasis on consulting with others in decision-making in the guidance. The Mental Capacity Act lays the responsibility for such decisions on the shoulders of the "healthcare professional who is in charge of the person's care" (see paragraph 9.64 of the Code of Practice).

The explanatory notes to the Act helpfully state that:

If the person has acted in a way that is clearly inconsistent with the advance decision remaining his fixed decision, then the advance decision is invalid. An example of an inconsistent action might be a former Jehovah's Witness converting to Islam and marrying a Muslim man. Even if she had forgotten to destroy a written advance decision refusing blood transfusion, her actions could be taken into account in determining whether that earlier refusal remained her fixed decision.

An advance decision will not be applicable if the person actually has capacity to make the decision when the treatment concerned is proposed. It will also not be applicable to treatments, or in circumstances, not specified in the decision. Furthermore the decision will not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the person and, if they had been anticipated by him, would have affected his decision. For example, there may be new medications available that radically change the outlook for a particular condition and make treatment much less burdensome than was previously the case.

An advance decision will not apply to life-sustaining treatment unless it is verified by a statement confirming that the decision is to apply to that treatment even if life is at risk. The reference to "life" includes the life of an unborn child. Both the decision and the statement verifying it must be in writing and be signed and the signature must be witnessed. It is important to note that a person does not physically need to write his advance decision himself. This means that advance decisions recorded in medical notes are considered to be in writing. Writing can also include electronic records. (See: <http://www.opsi.gov.uk/acts/acts2005/en/05en09-b.htm>).

It is important that the guidance emphasises these statutory safeguards to advance decisions and explains them with some examples. These points are more fully explained in the Mental Capacity Act Code of Practice which gives the following helpful example:

Scenario: Assessing whether an advance decision is valid

A young man, Angus, sees a friend die after prolonged hospital treatment. Angus makes a signed and witnessed advance decision to refuse treatment to keep him alive if he is ever injured in this way. The advance decision includes a statement that this will apply even if his life is at risk. A few years later, Angus is seriously injured in a road traffic accident. He is paralysed from the neck down and cannot breathe without the help of a machine. At first he stays conscious and gives permission to be treated. He takes part in a rehabilitation programme. Some months later he loses consciousness. At this point somebody finds his written advance decision, even though Angus has not mentioned it during his treatment. His actions before his lack of capacity obviously go against the advance decision. Anyone assessing the advance decision needs to consider very carefully the doubt this has created about the validity of the advance decision, and whether the advance decision is valid and applicable as a result.

It goes on to state:

Deciding whether an advance decision is applicable

...

9.42 The advance decision must also apply to the proposed treatment. It is not applicable to the treatment in question if (section 25(4)):

- the proposed treatment is not the treatment specified in the advance decision
- the circumstances are different from those that may have been set out in the advance decision...

9.43 So when deciding whether an advance decision applies to the proposed treatment, healthcare professionals must consider: ...whether there have been changes in the patient's personal life (for example, the person is pregnant, and this was not anticipated when they made the advance decision) that might affect the validity of the advance decision...

This selection provides some necessary detail regarding decision-making in the area of advance refusals of treatment. (See: <http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>).

Conscientious Objection

We are pleased to note that the guidance covers the essential topic of conscientious objection, but it is not detailed enough. For example, the Mental Capacity Act Code of Practice states that arrangements should be made for the management of the patient's care to be transferred to another healthcare professional. The Code of practice in 9.38 states that "where a transfer cannot be agreed, the Court of Protection can direct those responsible for the person's healthcare (for example, a Trust, doctor or other health professional) to make arrangements to take over responsibility for the person's healthcare." This implies that the transfer of care does not have to be as immediate as the suggestion being implied in this draft guidance and should therefore stress that whilst arrangements are being made the doctor concerned is not expected to act against his conscience. (See: <http://www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf>).

The obstacles to following this advice may arise if there is an absence of a supportive environment.

The guidance should make it clear that conscientious objections and personal beliefs should be fully respected and the diversity of belief supported at all levels. No doctor at whatever level should suffer any discrimination (direct or indirect), victimisation or any detriment as a result of conscientious objections. There is a need for employers and colleagues to support the diversity of belief not only amongst patients, but also amongst staff, particularly the beliefs of junior doctors and other healthcare professionals.

Care After Death—Organ Donation

The Care after Death section adequately addresses the key issues that need to be considered assuming a patient is actually dead. There has been much concern in recent months that patients might not be completely dead when their organs are removed. See for example, the article entitled “The Dead Donor Rule and Organ Transplantation”, *The New England Journal of Medicine*, 14th August 2008 at: <http://content.nejm.org/cgi/content/full/359/7/674?query=TOC>. See also *The Daily Mail* article of 10th July 2009, “Imagine hearing doctors discuss whether to kill you. It happened to me...” at: <http://www.dailymail.co.uk/debate/article-1198731/BARONESS-CAMPBELL-Imagine-hearing-doctors-discuss-kill-It-happened-.html>.

We believe that it is essential to provide a definition of “death”, so that doctors know when the section on “Care after Death” applies. A suggested definition in relation to brain death is the “complete absence of all functions of the entire brain”, as mentioned in the above journal article.

The guidance seems to imply that organ donation should be raised with those close to the patient in all cases. There is no indication that there are circumstances where it might be inappropriate to do so, unless a person already has that understanding and reads between the lines. The appropriateness of consulting relatives about possible organ donation should be made more explicit in the guidance.

The guidance should also state that if a deceased patient’s tissue is intended for any other use such as research, consent should be sought for the uses to which the deceased’s tissue is to be put and an explanation given to the deceased’s relatives. There is now a possibility of creating embryos or human admixed embryos from the tissue even of deceased patients and it is likely that many will have moral or religious objections to such unethical research. It is important that donating a body to scientific research does not allow such usage and fully respects the beliefs of deceased patients and their relatives.

It is stated that 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. However, there is a real danger that decision-making may incorrectly be determined by issues such as the shortage of donors when making decisions on a patient’s best interests. The guidance must make it clear that the doctor must always act in the interests of prolonging the patient’s life and must never consider organ donation when making decisions about end of life care.

It is thus essential that the separation of roles between those providing treatment to a patient and those deciding whether the patient would be a suitable organ donor is maintained rigorously. This does not mean, however, that the team who were providing treatment to a patient who has since died should be unable to pass information to the transplant co-ordinator.

Making Sound Clinical Judgments

As an organisation, we acknowledge that there will be times when doctors will have to make judgments that are in the patients' best interests. At times, the application of the said principles might be difficult and therefore we encourage a sound and stringent application of them to each individual situation.

What has happened previously is that options are discussed only when a critical point has been reached for patients; we support the consultation's proposal that doctors should consider the long-term options including palliative care. While each situation is contingent on the subjective judgment of the doctor, we would hope that doctors would adhere to the practices of their profession and put their patients' best interests first.

Explaining the Clinical Issues

The principles that have been outlined by the GMC with respect to the explanation of clinical issues is agreed upon, including the need for adequate and informed communication, which is vital to a patient's well-being and medical treatment.

We believe that doctors are to be a source of support to the families, this belief being shared by many in the profession. Medical treatment is often an emotional time and therefore strong support is valued.

We draw particular reference to paragraph 47 subsection (f)—*The Patient's needs for religious, spiritual or other personal support*. We understand the value of spiritual support and believe that this should be stressed as an option. Further, we believe that if doctors are interested in encouraging their patients in the Christian faith, they should have the autonomy to do so and should not be penalised. It has been decided that those in the medical profession should not and do not have to set aside their faith in the work place. We believe that the guidance should stress the importance of spiritual needs as an element of care for every patient. Attention to a patient's spiritual needs should not be limited to end-of-life care.

Neonates, Children and Young People

We believe that strong adherence to the established legal principles in society as they relate to children undergoing medical treatment should be adhered to. This demographic is valued as much as adults. Because of this value in life regardless of age, we believe that specific attention is necessary to

ensure that children are provided with the best possible care. There is a subtle trend occurring where children are wishing to assert their autonomy in relation to their bodies as seen with the recent case law of *Gillick* and *Axon*. We support respect for the role of parents in making important decisions for their children and the proper consideration of each person's rights.

Special Challenges in Applying the Guidance

Clinically-assisted nutrition and hydration

The change in language is supported as it removes the negative connotation and stigma associated with this technique. We believe that this area has caused much controversy due to lack of adequate knowledge of the processes.

As an organisation rooted in Christian principles, we do not support any attempts to encourage euthanasia or assisted dying. We mention the subject because the methods outlined in paragraphs 83-97 can be used to end one's life and Parliament has very recently agreed that this should never be an option.

It is of concern that paragraphs 83 to 88 read as if the main principle of prolonging life stated at the start of paragraph 89 and 90 does not apply. The impression is given on reading this part of the guidance that consideration will be given to the prolonging of the lives of those without capacity using clinically assisted nutrition or hydration, whereas those with capacity have an absolute right to these procedures. Paragraph 89 (which applies where patients have capacity) starts with: "If clinically assisted nutrition or hydration might prolong a patient's life, and that patient has capacity to make decisions about their care, *you must offer* these treatments to the patient" (our emphasis).

On the other hand, where paragraph 90 applies because the patient lacks capacity, the guidance begins: "If clinically assisted nutrition or hydration might prolong the life of a patient who lacks capacity to decide, *you must be prepared to provide* these treatments" (our emphasis). It is surely not right that the lives of patients who have the ability to express themselves should enjoy greater protection than those who do not.

We agree with and support the belief in paragraph 87 that clinically assisted nutrition should be regarded as basic nurture and should always be provided. In some cases, patients and those close to them, or members of the healthcare team, may have strong beliefs that clinically-assisted nutrition and hydration are not medical treatments, but part of basic nurture for the patient and should always be provided. In considering such matters, doctors need to be aware of human rights legislation including article 9 of the European Convention on Human Rights, which enshrines the freedom of thought, conscience and religion and article 2 which outlines the right to life.

We do not support any efforts that encourage the ending of life and we would ask that those in the medical profession be held to the highest level of accountability to ensure that this does not happen.

Additional Comments

We believe that the essence of the guidance and its aims are well intentioned; as it demonstrates support in valuing patients.

While in principle the aims of the consultation are good, they will only have a beneficial effect if doctors apply them stringently on the presumption in favour of prolonging life. The value of life and the patients' best interests should be the main concern of the medical community.

The draft guidance values patients and endeavours to ensure their well being during this difficult stage, which for us always needs to be coupled with ensuring the sanctity of patients' lives.