

SUBMISSION OF THE JOINT MEDICAL ETHICS COMMITTEE OF THE CATHOLIC MEDICAL ASSOCIATION AND THE CATHOLIC UNION OF GREAT BRITAIN TO THE GMC CONSULTATION ON “END OF LIFE CARE: GOOD PRACTICE IN DECISION-MAKING” July 2009.

PART I: RESPONSE TO CONSULTATION QUESTIONS

Introduction (paragraphs 9-12)

Q1. Do you agree that the Introduction (paragraphs 9-12) sets out the scope of the guidance clearly?

No

It is not always possible to determine the “end of life” or when patients have entered the ‘terminal phase’ of their illness.

The criteria for determining the dying phase in the Liverpool Care Pathway are that the person is judged by the responsible team to be terminally ill and that two of the following criteria apply: the patient is bed bound, semi-comatose, unable to take oral medication and/or unable to take oral food and fluids. Whilst this may be appropriate for those with incurable cancer, when being bedbound and semi-comatose may well mean that the patient is near death, it is not necessarily true of other incurable though ‘benign’ diseases such as motor neurone disease. In MND the patient whilst having an incurable and eventually fatal disorder may be bedbound and unable to swallow tablets or food and fluids, for years or even months before they die. Similarly those with chronic lung or heart disease may have repeated life-threatening exacerbations from which they recover despite periods of being bedbound and unable to swallow.

Notwithstanding the diagnostic errors inherent in any estimation of whether a patient has entered the ‘dying phase’, we suggest that it might be more useful to ask four basic clinical questions in determining whether the patient is terminally ill and death is imminent. We suggest that a positive answer would be necessary to all four questions before accepting that the patient had entered the “dying phase”.

First, is the patient suffering from a known terminal illness which in the view of the treating physician is likely to result in cardio-respiratory arrest within the next 48 hours?

Second, are extraordinary means contraindicated, because they are considered to be unlikely to work in the judgement of a responsible doctor or thought to be excessively burdensome by the competent patient or his or her legal representative?

Third, have ordinary life saving therapies become futile? Would therapies that would usually be considered to be ordinary and proportionate means of saving life be unlikely to save the life of the patient for more than 48 hours?

Fourth, has basic care, including hydration and nutrition been given to the patient up until the time that the diagnostic assessment of the “dying phase” was made?

End-of-life care is based on a perception that the patient is near death and the prognosis can be held with certainty. The type of care the patient then receives, or not, is then predicated on the view that the patient is in the dying phase. According to the Liverpool Pathway, once the patient is deemed to be in the dying phase, ‘inappropriate’ observations, investigations and treatments are stopped. Often hydration is discontinued and patients are given subcutaneous infusions of the opiate diamorphine, sedatives such as midazolam and hyoscine (this has antisecretory and sedative properties). The use of this regimen may induce ‘terminal sedation’ in patients. Whilst there is provision to review, modify and stop the LCP, the cessation of hydration coupled with the use of opiate, sedative and hyoscine, will inevitably cause a decline in the patient’s condition, unless the patient is already in the agonal stages of the disease.

In reality, palliative care, which can be defined as the relief of symptoms when cure is no longer appropriate, or even possible, should be applied irrespective of whether the patient is considered ‘terminally ill’ or in the ‘dying phase’. Where treatment cannot be curative, the relief of symptoms and the restoration of function become important. Palliative care (our preferred term) is appropriate for those who are likely to die as well as those with non-terminal but incurable conditions. Good palliative care does not need to be predicated on the assumption that the patient is dying.

For patients and their relatives to be told that the patient is receiving ‘end of life care’ may be not only distressing but inaccurate.

Paragraph 9 seems to equate ‘end of life care’ with having a ‘life-limiting’ condition. However conditions such as cancer, dementia and PVS are not necessarily terminal conditions. Furthermore ‘life threatening acute conditions caused by sudden catastrophic events’ are not necessarily terminal so that it is difficult to understand why they should necessarily be the subject of ‘end of life care’. There are only three references to ‘life-limiting’ conditions in the guidance in paras 1, 77 and 99. Since only category (a) actually refers to life-limiting conditions which may improve, it is difficult to see the value of paragraph 9.

We suggest retention of the well understood and established term ‘palliative care’ rather than ‘end-of-life care.’

Equalities and human rights (paragraphs 13-15)

Q2. 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?

Yes

Human rights issues may arise under Article 2 (“right to life”); Article 3 (“freedom from inhumane and degrading treatment”); Article 8 (“right to private and family life”) and Article

9 (“freedom of thought, conscience and religion”). The GMC must apply its professional rules in a way that is compatible with the Convention.

Article 2.

Under Article 2 the “State is under an obligation to adopt appropriate (general) measures for protecting the lives of patients in hospitals. This will involve, for example, ensuring that competent staff are recruited, that high professional standards are maintained and that suitable systems of working are put in place” (Savage v South Essex Partnership NHS Foundation Trust [2008] UKHL 74 para 74). It is the function of the GMC to maintain high professional and ethical standards amongst health professionals for the protection of the lives of patients. Health authorities are under an over-arching obligation to protect the lives of patients in their hospitals (Savage [2008] UKHL 97 para 68) and as part of that duty must ensure that hospitals “employ competent staff and that they are trained to a high professional standard” (Savage [2008] UKHL 74 para 69). Positive obligations also arise under Article 3 requiring States to take measures designed to ensure that individuals within their jurisdiction are not subjected to inhumane and degrading treatment or punishment.

Vulnerable adults may have difficulties in accessing good quality care throughout life and not only when they are deemed to be dying. Article 2(1) requires the State not only to refrain from the intentional and unlawful taking of life (the negative obligation) but also to take appropriate steps to safeguard the lives of those within its jurisdiction (the positive obligation).

Article 3.

The withdrawal of hydration (or nutrition) could infringe Article 3 if the patient suffered severe thirst or the effects of starvation thereby exposing the patient to “inhumane or degrading treatment”. The way in which a patient is treated is capable of being “degrading” within the meaning of Article 3, whether or not there is awareness on the part of the victim. Hence, maltreatment which has the effect on witnesses, such as relatives, of degrading, debasing or humiliating the individual or showing a lack of respect for his or her human dignity would engage Article 3.

Article 9.

This applies to the issue of conscientious objection to the withdrawal and withholding of life sustaining treatment (see later concerning changes to paragraph 67). Under Article 9 “everyone has the right to freedom of thought, conscience and religion either alone or in community with others and in public or private, to manifest his religion or belief, in worship, teaching, practice and observance.” This freedom to “manifest one’s religion or beliefs shall be subject only to such limitations as are prescribed by law and are necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others.” The GMC must apply its

professional rules in a way that is compatible with Part 2 of the Equality Act 2006, section 45(3) so as to avoid discrimination on the basis of religion or belief.

The courts have been reluctant to order doctors to treat a patient in a particular way, especially if it was contrary to their clinical judgement. (See for example the Court of Appeal in *re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15). We do not believe that a doctor should be put in a position where he may be required to choose between his conscience and imprisonment for contempt. Moreover, we cannot envisage circumstances in which a court would act so as to place a doctor in such an unenviable position.

Presumption in favour of prolonging life (paragraph 16)

Q3. Do you agree that the advice in paragraph 16 strikes a reasonable balance between these factors?

Yes

As outlined later it is important to distinguish basic care from medical treatment. There is a fundamental obligation to provide sustenance to patients unless the patient is dying within hours or days. The exact means of delivery of hydration and nutrition will depend upon individual circumstances. Where a patient is completely unable to swallow or is at significant risk of aspiration, the offer of oral food and fluids would not only be inappropriate but even dangerous. To fail to provide hydration might well lead to acute physical and psychological distress in the patient and breach Article 3 by subjecting the patient to inhumane and degrading treatment.

Clause 44 of the Mental Capacity Act creates the offence of ill-treatment or wilful neglect. The term 'neglect' was defined by Thomas Bingham (MR) as "a gross failure to provide adequate nourishment or liquid, or provide or procure basic medical attention or shelter or warmth for someone in a dependent position (because of youth, age, illness or incarceration) who cannot provide it for himself. Failure to provide medical attention for a dependent person whose physical condition is such as to show that he obviously needs it may amount to neglect". (*R v. HM Coroner for North Humberside and Scunthorpe, ex parte Jamieson* [1995] QB 1 at 25).

Making sound clinical judgements (paragraphs 21-24)

Q4. 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

We feel that the guidance will be useful in encouraging doctors to focus on the palliative care needs of patients. We prefer the term 'palliative care' over 'end-of-life' care because not only

is prognosis difficult but palliative care is not only applicable to those who are terminally ill but includes symptom control in patients where cure is no longer possible or appropriate.

Q5. 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

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

Q6. 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?

Not sure

We hope that the overall tenor of the document will be helpful to patients, families and carers. However, we are not convinced that the section on emotional difficulties and especially paragraphs 28, 29, 30, 31 and 32, will necessarily help. A few of our respondents have commented that the GMC document is perhaps unduly long and might be engaging problems which cannot be easily settled in guidance of this nature. We therefore suggest deletion or modification of paragraphs 28, 29, 30, 31 and 32 as they seem to add little to the document, or may even lead to further doubts.

Paragraph 28.

Paragraph 28 may have the effect of encouraging doctors to provide very aggressive medical therapy in those with little hope of recovery. A not infrequent example is the provision of CPR and then ventilation to a patient who has survived a cardiac arrest but who is almost certainly profoundly brain damaged and with little hope of survival. Stopping the ventilation at a later date may be very distressing for the relatives and others. Paragraph 28 assumes that stopping treatment, or not starting it in the first place, is always morally equivalent. In practice there is almost always a difference in so far as treatment alters the circumstances of the patient. Therefore, what has hitherto been an uncertain or hypothetical outcome becomes clear once the treatment is applied. Following treatment, a new set of clinical circumstances arise with a further set of possible future outcomes that have to be considered. Paragraph 28 engages deep ethical issues yet presents real dilemmas as if they were straightforward. The assumption that we can always pull out of a treatment may encourage very aggressive and often futile intensive care of patient which is traumatic for the patient and the relatives. All

too often an uncritical approach to the initial aggressive treatment does leave doctors and relatives with difficult decisions to consider later. In the case of PVS patients, whose condition only arises after persistent aggressive intensive care, we do not accept that their death should be deliberately brought about through dehydration, notwithstanding that further aggressive treatment of supervening complications ('relentless therapy') may not be indicated.

Paragraph 29.

It may not be possible in a GMC document aimed at giving overall advice and general principles, to address matters of uncertainty in a satisfactory way. For example, it may be practically impossible to determine exactly how long a treatment should be tried for or what would be a successful outcome. Responses may be partial or there may be unexpected side effects of treatment. It may therefore be difficult to define precisely beforehand the basis of continuing or stopping the treatment. We have some concern about the GMC going too far into these difficult and contentious areas.

We believe that these difficult and contentious issues cannot easily be resolved within the context of GMC advice, much less that there should be any question of sanction against doctors unless wrongdoing is clearly established, which we believe would be difficult to establish in practice and would depend upon the precise circumstances of the case. Addressing uncertainty is after all, by definition difficult.

Suggestion. To delete or modify these paragraphs 28 and 29.

Paragraph 30

It is perhaps unwise to dismiss the very real ethical decisions surrounding the commencement or cessation of life-sustaining treatment as emotional reactions. Whenever life sustaining treatment is started the clinical situation of the patient alters so that a new ethical situation arises. For example, a decision to undertake, or not, full cardiopulmonary resuscitation ought to be taken like any other clinical decision in the light of the risks and benefits of the treatment to the patient. However, it has become commonplace to take the initial decision to resuscitate very readily and then to be faced with much more difficult decisions regarding the extent to which the patient ought to be supported at a later date. In neurosurgical practice when treatment for head injury is discontinued e.g. mechanical ventilation, the issue of whether the patient may have died as a result of stopping treatment has medico-legal significance for any assailant. Defendants in cases of assault when faced with murder or manslaughter charges might argue that the death was caused by the failure to continue medical intervention. Relatives who are asked to 'agree' to the cessation of intensive care may well feel that they have been party to the death of a loved one. Paragraph 30 makes it unclear as to whether the clinician or relatives are making the decisions. It is distressing to make the relatives feel that the responsibility to discontinue mechanical ventilation is up to them. Some relatives are even given an apparent 'choice' as to whether to continue intensive care when the reality is that the patient is likely to die with or without treatment. When patients are acutely ill with life-threatening conditions the relatives are not in an emotionally fit state to be making such decisions and may welcome clear directions from the clinicians.

When tube feeding is regarded as life-sustaining ‘medical treatment’ relatives may well feel (with justification) that withdrawal of hydration and nutrition is bringing about i.e. causing death rather than the patient’s underlying condition.

Paragraph 31

Paragraph 31 is a statement of the obvious need to monitor a patient which should normally be part of good clinical practice. To introduce the notion that the patient’s condition may improve ‘unexpectedly’ raises issues over the doctors’ competence regarding diagnosis and prognosis of the patient. The last sentence is somewhat ambiguous. Is the unexpected improvement due to the treatment or is the implication that it is spontaneous?

Paragraph 32

Paragraph 32 seems largely redundant. One would hope that patients would not be unduly pressured in making decisions regarding their own treatment and that clinicians would always support relatives during emotionally difficult times.

Q7. 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?

Not sure

Good communication requires a competent assessment of the patient’s condition and the reasonable treatment options. There is no ethical or legal obligation to offer inappropriate or futile treatments. Indeed, to do so might undermine confidence in the clinician. It is important to distinguish real decisions, where the views of relatives and other carers will be taken into account from ‘apparent’ decisions. Apparent decisions arise where there are no worthwhile treatment options and relatives are asked to ‘agree’ to discontinue treatment. When the patient dies after stopping (ineffective) treatment, relatives may feel that their agreement has contributed to the death of their loved one. Whilst doctors may forget the patient within a short period of time, the relatives may live with the memory for years without realising that the patient would have died irrespective of their apparent decision to stop treatment.

Some patients although invited to contribute to the medical decision-making may nevertheless be too emotionally involved and be consequently unable to see things objectively. This may be a problem for donees of Lasting Power of Attorney who may have been empowered to make healthcare decisions. The problems of duress of circumstances, especially when the illness has been sudden and unexpected, and of emotional duress should be considered. In other words, the mental (in)capacity of the patient’s legal representatives may need to be considered where the decision-making rests with a proxy decision maker.

Resource constraints (paragraphs 33-35)

Q8. 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.

Not sure

Issues relating to the allocation and use of scarce medical resources are complex and at times contentious. They are not amenable to easy solutions and pose considerable practical problems. Moreover, whilst doctors ultimately use resources, the acquisition and provision of such facilities are outside of their control

It is difficult to see how paragraph 33 could be applied in practice. How will the treatment of a particular patient be explained to relatives in relation to duties to the “wider population, funding bodies and employers.” How can a proper balance be made between these competing interests? It may be difficult, or impossible, to explain to a patient or relatives that a decision not to apply efficacious treatment is based upon duties to employers or local policies.

Paragraph 33 appears to be a significant breach of the general principle that “I will make the care of my patient my first concern” (Good Medical Practice”). It is most unlikely that “the wider community, funding bodies and employees” will ever directly enter into dialogue with those immediately involved in these difficult individual decisions. Nor is it easy to see how such decisions are to be made on the basis of local or national policy in a way that takes account of human rights implications which are unfamiliar to most doctors.

Unfair discrimination presumably applies more (or even exclusively) to a failure to provide treatment for patients. Paragraph 33, whilst admitting to ‘no simple solutions’ is nevertheless requiring, or even permitting, doctors to take decisions which may be contrary to the interests of individual patients on the basis of wider responsibilities. If this is indeed the case, will doctors be free from liability or censure on the basis that they have acted at the behest of employers or in response to service cuts?

Suggest delete all but first sentence of paragraph 33. By contrast, paragraph 34 gives advice as to what needs to be considered in making decisions for individual patients where there are resource limitations, it quite properly does not prescribe exactly how such decisions must be made.

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

Q9. 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?

Not sure

It is important to be clear that paragraph 37 refers to medical treatment and not to the provision of hydration and nutrition.

For the avoidance of doubt we would therefore suggest the following changes to paragraph 37:

37. You must not start or continue with a potentially **medical** life-prolonging **medical** treatment if the patient with capacity has refused it, and should not normally do so where the patient lacks capacity to decide and it is agreed that **such** treatment would not be of overall benefit to them. It may also be of no overall benefit to provide potentially life-prolonging treatments in the last days of a patient's life when the focus of care is changing from active treatment to palliation of symptoms and relief of the patient's suffering. **There should however, be a strong presumption in favour of the provision of hydration and nutrition.**

We also feel that paragraph 41 would be strengthened by a reference to non-discrimination on the basis of age and disability. A doctor's role is to decide the best treatment for the patient in his or her particular circumstances and not to judge whether a patient's life is worth living.

Suggested change to paragraph 41.

41. You must be careful not to rely on your personal views about a patient's quality of life or make judgements based on poorly informed or negative views about the healthcare needs of particular groups, such as older people and those with disabilities. **It should not be part of a doctor's role to decide whether a patient's life is worth living and such judgments should never form part of the rationale for treatment.**

Advance care planning (paragraphs 43-53)

Q10. 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.

Yes

However, in the last sentence of paragraph 51 we would suggest deletion of the word 'clinically' before "assisted nutrition and hydration".

To read:

"Some patients may hold strong views about receiving assisted nutrition and hydration towards the end of their life, because they see these not as medical treatment but part of basic care".

Recording and communicating decisions (paragraphs 62-65)

Q11. 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

The Mental Capacity Act did not give statutory force to legally binding positive advance decisions. This would have resulted in a statutory duty to provide treatment which may have been clinically inappropriate or even harmful. The question as to how far doctors must

comply with reasonable advance requests by patients for treatment has been a matter of common law rather than statute.

Doctors will usually advise patients as to a range of therapeutic options (including non-treatment) according to the circumstances. Of course, patients consent to treatment in advance of it being provided. In this sense, all consent is given in advance of treatment. In normal medical practice, consent is only considered valid if given close to the time of the proposed treatment. However, advance refusals do not have this time constraint and may be made months or even years in advance of the treatment being given. The question therefore arises as to the extent to which doctors should be obliged or expected to carry out the wishes of patients regarding future treatment when they become mentally incapacitated.

Lord Phillips made a number of clear statements regarding the duty of doctors towards patients in the case of *Burke* ([2005] EWCA Civ 1003).

“Autonomy and the right of self-determination do not entitle the patient to insist on receiving a particular medical treatment regardless of the nature of the treatment. Insofar as a doctor has a legal obligation to provide treatment this cannot be founded simply upon the fact that the patient demands it. The source of the duty lies elsewhere” (para 31).

“Once a patient is accepted into a hospital, the medical staff come under a positive duty at common law to care for the patient” (para 32).

“A fundamental aspect of this positive duty of care is a duty to take such steps as are reasonable to keep the patient alive. Where ANH is necessary to keep the patient alive, the duty of care will normally require the doctors to supply ANH (para 32).

“Where the competent patient makes it plain that he or she wishes to be kept alive by ANH, this will not be the source of the duty to provide it. The patient's wish will merely underscore that duty” (para 32).

“It seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder” (para 34).

Hence, following *Burke*, the doctor has an underlying duty of care at common law once the patient has been admitted to hospital. A fundamental aspect of this positive duty is to take reasonable steps to keep the patient alive. Where ANH is necessary to sustain life, the duty of care will normally require the doctors to provide it. A deliberate failure to provide ANH in the face of a competent patient's wish to receive it, with the intention of causing the patient's death “would leave the doctor with no answer to a charge of murder.” Autonomy and self-determination do not entitle the patient to insist on receiving any particular treatment regardless of its nature, risks, benefits and alternatives.

Suggested change to paragraph 55.

55. Where death is imminent (within a few days or within hours), and the burdens of continuing a potentially life-prolonging treatment outweigh any possible benefits to the patient, it usually **may** be appropriate to stop the treatment, while focusing on meeting the patient's needs for palliative care and effective symptom management. Where a patient has previously requested that the treatment be continued **in the event of mental incapacity, there remains a presumption in favour of giving it. However, the Courts have accepted that where life involves an extreme degree of pain, discomfort or indignity to a patient, who is sentient but not competent and who has manifested no wish to be kept alive, the circumstances may absolve the doctors of the positive duty to keep the patient alive. Where ANH is necessary to sustain life, the duty of care will normally require the doctors to provide it. Indeed, according to Lord Phillips in *Burke*, a deliberate failure to provide ANH in the face of a competent patient's wish to receive it, with the intention of causing the patient's death "would leave the doctor with no answer to a charge of murder."**If significant disagreement arises between you and the patient's representative or those close to them, or members of the healthcare team, about what would be of overall benefit to the patient, you must take steps to resolve this (see paragraphs 77-78 of *Consent: patients and doctors making decisions together* for guidance on resolving disagreements).

Q12. 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

Many patients wish to die at home. However, this is not always possible because of intercurrent medical illness requiring hospitalization and because relatives are not always able to manage the sometimes demanding requirements of caring for the dying. There may also be logistical and financial implications of providing domiciliary palliative care and medical supervision of patients in the community.

Q13. Do you think the guidance makes clear how doctors should decide whether a patient's advance refusal of treatment should be acted on?

No

An advance refusal of treatment could have serious repercussions for the patient particularly if made a long time in advance when the patient was not suffering from the condition in question and may have had little idea as to the effectiveness of treatment, or indeed, of any advances in treatment since the refusal was made. We therefore suggest a number of changes in the draft document to reflect this.

Paragraph 58.

Paragraph 58 suggests that advance refusals often do not come to light until the patient has lost capacity. What is the evidence that advance refusals are not discussed beforehand with relatives, carers or healthcare professionals?

If the advance refusal refers to life-sustaining treatment it must be in writing, signed and witnessed. (However, changes to the written advance refusals may be made orally which will clearly cause evidential problems).

According to guidance from the BMA and Law Society, any medical witness to a document such as an advance refusal would not only be a witness of fact but an expert regarding the issue of capacity. Therefore, if a doctor is witnessing an advance refusal, it would be appropriate for the doctor to ensure that the patient was aware (in so far as it was possible) of the consequences of making such an advance refusal. It would also be helpful for the doctor to record the patient's level of understanding when making the advance refusal and the limitations of such statements, especially in relation to conditions and treatment that patient had not experienced.

Suggested changes to paragraph 58 (including deletion of the last sentence).

58. Advance refusals of treatment **may** not come to light until a patient has lost capacity **However, advance refusals which refer to the cessation of life-sustaining treatment must be in writing, signed and witnessed. If the witness is a doctor (s)he must ensure that the patient not only has mental capacity but understands the implications of non-treatment. Whilst there is no legal requirement to discuss advance refusals with medical professionals, a failure to do so might raise questions as to their validity and applicability at a later date.**

Paragraph 59

It may also be appropriate to consider the extent to which the patient discussed the treatment options with a healthcare professional to determine the understanding of the patient when making the advance refusal. It is also important to consider any advances in treatment that may have occurred since the advance refusal and whether such developments would have been likely to have been considered by the patient or influenced their decision. For example, a refusal of cancer treatment may have been based upon experience with a relative or parent many years before

According to s(24)(4)(c) of the Mental Capacity Act:

An advance decision is not applicable to the treatment in question if there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

We suggest the following changes to paragraph 59:

59. In deciding whether the advance refusal of treatment is clearly applicable to the circumstances that have arisen, you should check whether the advance refusal specifies particular treatments or circumstances when the refusal should apply. You should consider how long ago the decision was made; **the contents of any discussions with healthcare professionals and the degree of understanding of the relevant treatments when the refusal was made;** whether it has been reviewed or updated; any relevant **therapeutic developments** or changes in the patient's personal circumstances since the decision was

made; any more recent actions or decisions of the patient that indicate they may have changed their mind. **An advance decision is not applicable to the treatment in question if there are reasonable grounds for believing that circumstances exist which the patient did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.**

Paragraph 60.

According to the MCA, a person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment (s.26(2)). Where the doctor is not satisfied as to the validity and applicability of an advance refusal there is no legal requirement to apply to Court although it may be advisable to do so where substantial disagreements arise or there is genuine doubt. When a court ruling is sought, treatment ought to be continued to prevent deterioration in the patient's condition (s.26(5)).

Suggested changes to paragraph 60:

60. According to the Mental Capacity Act, a person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment. If there is doubt or disagreement about the validity or applicability of an advance refusal of treatment you should make further enquiries, where time permits, and seek a ruling from the court where necessary. **However where a court ruling is sought, treatment that the doctor reasonably believes is necessary ought to be continued to prevent a deterioration in the patient's condition.** In an emergency, where there is no time to investigate further, the presumption should be in favour of providing treatment, if it has a realistic chance of prolonging the patient's life.

Recording and communicating decisions (paragraphs 62-65)

Q14. 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?

No

Disagreements may arise regarding the withholding and withdrawing of care and treatment which may give rise to future complaints. The importance of documentation arises when decisions are challenged so that it is necessary to indicate what, if any, disagreements arose at the material time and how they were resolved. It is only in this way that the doctor would be able, where necessary, to justify his/her actions and demonstrate that (s)he had acted in the patient's best interests.

Suggested changes to paragraph 62.

62. Disagreements may arise regarding the withholding and withdrawing of care and treatment which may give rise to future complaints. You must make a record of the decisions made about a patient's treatment and care, and who was consulted in relation to

those decisions. **Where complaints have arisen, the contemporaneous record of any disagreements and the way they were resolved, may be taken in evidence to determine whether or not the doctor had acted reasonably and in the ‘best interests’ of the patient.**

Conscientious objections (paragraph 67)

Q15. Do you agree that the guidance makes 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?

No

It is important to distinguish between ‘personal beliefs’ and ‘clinical and professional judgement’. For example, a doctor may have a conscientious objection to withdrawing life-prolonging treatment where the objection would also be in accordance with good clinical practice. A particular difficulty arises with the withdrawal of assisted hydration. Unless the patient is imminently dying within hours or days of the underlying disease, the cessation of hydration will inevitably cause the patient’s death. This raises the question of the motive of either the patient acting through an advance refusal or a donee of lasting power of attorney in deciding such a course of action. Intentionally causing death through dehydration would not be in a patient’s ‘best interests’. Clause 4 (5) of the MCA specifically excludes being “motivated by a desire to bring about the death of the patient” as a legitimate consideration in deciding ‘best interests’. Also wilful neglect is a criminal offence under the Act (s. 66) in so far as deliberately causing the death of the patient would constitute neglect or even manslaughter.

If conscientious objection became punishable i.e. it were to become a matter of professional misconduct, there would be issues under Article 9 of the Human Rights Act 1998 which protects Freedom of Religion. Under Part 2 of the Equality Act 2006 it is illegal for public authorities, including the GMC, to discriminate against people because of their religion. There could also be employment issues since under the Employment Equality (Religion or Belief) Regulations 2003, it is illegal for employers to discriminate against employees or applicants for jobs because of their religion.

However, since the Mental Capacity Act provides for resolution of disputes through the Court of Protection, which has the power under section 17 to allow the transfer of the patient to the care of another doctor, we feel that it is most unlikely that conscientious objectors would be subject to disciplinary action by the GMC.

Suggested changes to paragraph 67:

67. The GMC, BMA and Mental Capacity Act Code of Practice recognise the right of doctors to conscientious objection regarding the withholding or withdrawing of life-sustaining treatment. There may rarely be occasions when you disagree with a patient’s decision to refuse life-prolonging treatment, or to a refusal of treatment by his or her legal representative (donee of lasting power of attorney or welfare attorney). Under such circumstances you should make every effort to resolve such disagreements

informally. In Scotland, you may refer to a second opinion doctor where the welfare attorney has refused to consent to treatment. In England and Wales, it may be necessary to refer unresolved disagreements to the Court of Protection. The Court of Protection has powers to allow the transfer of the patient to the care of another doctor. Life-sustaining treatment ought to be provided to ensure that there is no deterioration in the patient's condition whilst a ruling is being sought from the Court. In those rare instances when it may be necessary to exercise your right of conscientious objection and to withdraw from the patient's clinical care, it is important to ensure that the wellbeing of the patient does not suffer in any way while another doctor takes over your role.

Q16. Can you think of any obstacles that would prevent doctors from following this advice in the different settings in which patients receive care?

Not sure

It is very difficult to imagine circumstances in which a doctor would be disciplined for conscientiously refusing to withdraw hydration from a patient who was not otherwise dying in order to deliberately cause the patient's death. In cases of disagreement the Mental Capacity Act provides a remedy through the Court of Protection. If a doctor with a conscientious objection has made his views clear and observed due process the Court would apply a solution. The nature of that solution would depend upon the circumstances of the case. However, once relieved of the legal responsibility for managing the patient through the appropriate legal processes, it is difficult to see how disciplinary proceedings could then be taken against the doctor.

Care after death (paragraphs 68-72)

Q17. Do you think this section gives sufficient detail about the key issues that need to be considered after a patient's death?

Yes

Q18. 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

Q19. Do you agree that this separation of roles will always be practicable?

Yes

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

Q20. *Do you know of any particular concerns about the treatment of neonates, children or young people that are not adequately covered in this guidance?*

No

Clinically assisted nutrition and hydration (paragraphs 83-97)

Q21. *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?*

No

The term “artificial nutrition and hydration” (ANH) is inappropriate as the nutrition and hydration itself is not ‘artificial’. The term usually refers to tube feeding by gastrostomy or nasogastric tube. It is therefore assisted feeding and little is gained by the use of the word “clinically”. In 2003 there were 16,890 adult patients undergoing home enteral tube feeding who were registered via the British Artificial Nutrition Survey. (Cited in National Collaborating Centre of Acute Care report on Nutrition support in Adults (2006) www.rcseng.ac.uk). Interestingly, according to this Report “in most cases, gastrostomy or jejunostomy tube feeding is used for convenience although some prefer to self-intubate with a nasogastric tube each time they need to feed or have long term NG tubes.” The fact that there are many patients who feed themselves or even place nasogastric tubes shows that tube feeding is a form of assisted nutrition.

The purpose of nasogastric or PEG tubes is not only to provide hydration and nutrition, but also to relieve distressing symptoms that would otherwise occur whilst eating, reduce the risk of aspiration and to provide a safe and convenient route for administering medication.

Oral nutrition and hydration is not appropriate or safe in those that cannot swallow or obtain sufficient oral nutrition and hydration. Some patients, for example those with severe learning disabilities combined with neurological impairment, may need careful spoon feeding by carers. Whilst this may be sufficient under normal circumstances, it may be very time consuming and fail if the patient becomes unwell for other reasons. An additional reason for the placement of a feeding tube may be to administer necessary medication e.g. if the patient is epileptic. Tube placement in such patients not only provides a secure means of feeding but a guaranteed route for the administration of necessary medication if the patient becomes unable to take oral drugs. Some patients with persistent swallowing problems after stroke may not be accepted in nursing homes with nasogastric tubes and therefore more permanent arrangements need to be made e.g. PEG placement. Patients with dysphagia are not only in need of assisted nutrition and hydration but also need to be protected from the risks of aspiration which may be troublesome and even frightening. We agree that swallowing difficulties should be managed effectively, even when this may be through tube feeding.

Suggested change to paragraph 84.

84. Where patients are unable to take sufficient nutrition and/or hydration by mouth, even with support, you must carry out an assessment of their condition and their individual requirements for nutrition and/or hydration. You must consider what forms of assisted nutrition or hydration may be required to meet their needs. **It is also important to ensure that those with swallowing difficulties are also relieved of other distressing symptoms such as choking and the fear of aspiration, for example by adequate mouth care and oropharyngeal suctioning.**

Q22. *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

Q23. *Do you agree that setting out these complicating factors is helpful?*

Not sure

Dysphagia (difficulty with swallowing) is always a distressing problem for patients. It may lead to anxiety and fears of choking. The relatively minor complications of tube feeding have to be weighed against the serious consequences and distress of dehydration and malnutrition as well as the anxiety or fear of choking whilst feeding. There is an increased mortality in stroke patients where PEG tubes are inserted within a month of the stroke, compared to those who are fed nasogastrically. Nevertheless, the low complication rate and convenience of PEG feeding after a month post-stroke outweighs the inconvenience and discomfort of nasogastric feeding.

The overwhelming advantages of tube feeding in those with significant swallowing disorders are reflected in the fact that there are no randomised controlled trials of the effects of tube feeding in patient unable to swallow as it would be completely unethical to conduct clinical trials in which patients were not fed in the 'control' limb. There are no trials comparing tube feeding with maintaining patients 'nil by mouth'.

The side effects and 'burdens' of assisted hydration and nutrition have been overemphasised in relation to the expected benefits in those patients who are not imminently dying. Dysphagia can be very distressing and ought to be relieved whenever possible. A variety of low risk procedures are now available which do not carry the substantial risks of older techniques. For example self-expanding metal stents which can be inserted endoscopically under sedation as 'day cases' have replaced the more rigid Nottingham and Atkinson tubes that carried a high rate of perforation and were usually placed under general anaesthetic.

The provision of hydration can always be achieved without undue hazard. Where nasogastric tubes are considered inappropriate, the subcutaneous route can be used to provide fluid, even in a domiciliary setting. Subcutaneous fluids are particularly useful in palliative care as they

do not require special monitoring and may obviate the need to admit dying patients to hospital.

PEG placement is now a low risk procedure. Once in situ the risks of use are no greater than for nasogastric feeding as shown in a recent audit by the British Society of Gastroenterology. PEG feeding is normally managed by carers or even the patients themselves. The risk of gastroesophageal reflux can be largely removed by the mode and timing of feeding, correct positioning of the patient and, where necessary, the use of pharmacological means to improve gastric emptying. In palliative care the use of subcutaneous fluids which does not require special monitoring enables patients to be managed at home and helps to obviate the need for hospitalisation of dying patients. Modern techniques of providing hydration and nutrition mean that the risks and burdens are not prohibitive and far outweigh the benefits in the overwhelming majority of patients.

We would therefore suggest the following changes to paragraph 85:

85. Assisted nutrition and hydration includes intravenous or subcutaneous infusion of fluids (use of a 'drip'), nasogastric tube feeding or administration of fluid, 'PEG' or 'RIG' feeding tube through the abdominal wall. These are techniques that may prolong and **significantly** improve the quality of a patient's life. However, **the range of techniques now available means that the problems and complications are usually minimal compared to the expected benefits.**

Q24. *Do you think that there are any other factors that should be included in paragraphs 85-87?*

Yes

We agree with the views expressed in paragraph 87. However, relatives may also have concerns where it appears that assisted nutrition and hydration is going to be withheld in order to bring about the death of the patient because of a perceived view of the patient's quality of life.

Suggested change to paragraph 87:

87. In the face of such uncertainties, concerns may arise about the possibility that a patient who is unconscious or semi-conscious, and whose wishes cannot be determined, might be experiencing distressing symptoms and complications or otherwise be suffering, because their needs for nutrition or hydration are not being met. Alternatively there may be concerns that attempts to meet a patient's perceived needs for nutrition or hydration may cause them avoidable suffering towards the end of their life. In some cases, patients and those close to them, or members of the healthcare team, may have strong beliefs that assisted nutrition and hydration are not medical treatments but part of basic nurture for the patient and should always be provided. **Relatives may also have concerns where it appears that assisted nutrition and hydration has been withdrawn in order to bring about the death of the patient because of a perceived view of the patient's quality of life.**

Q25. 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

We suggest changes to paragraph 55 to take into account the judgment of Lord Phillips in *Burke*.

55. Where death is imminent (within a few days or within hours), and the burdens of continuing a potentially life-prolonging treatment outweigh any possible benefits to the patient, it usually **may** be appropriate to stop the treatment, while focusing on meeting the patient's needs for palliative care and effective symptom management. Where a patient has previously requested that the treatment be continued **in the event of mental incapacity, there remains a presumption in favour of giving it. However, the Courts have accepted that where life involves an extreme degree of pain, discomfort or indignity to a patient, who is sentient but not competent and who has manifested no wish to be kept alive, the circumstances may absolve the doctors of the positive duty to keep the patient alive. Where ANH is necessary to sustain life, the duty of care will normally require the doctors to provide it. According to Lord Phillips in *Burke*, a deliberate failure to provide ANH in the face of a competent patient's wish to receive it, with the intention of causing the patient's death "would leave the doctor with no answer to a charge of murder."**If significant disagreement arises between you and the patient's representative or those close to them, or members of the healthcare team, about what would be of overall benefit to the patient, you must take steps to resolve this (see paragraphs 77-78 of *Consent: patients and doctors making decisions together* for guidance on resolving disagreements).

Suggested changes to paragraphs 92 and 93: Consider deleting paragraph 93 and perhaps modifying paragraph 92 as follows:

92. Where a **patient's death is imminent within** a matter of hours or **a few days**, and you consider that nutrition or hydration will not prolong their life, it **may not be** appropriate to start **or continue tube feeding**. However, you should assess the need for nutrition or hydration separately. For example, fluids may still provide symptom relief when nutrition is no longer of any overall benefit to the patient.

If these changes were made to paragraph 92, paragraph 93 would become redundant. Otherwise we would suggest changes to paragraph 9.3. The last sentence should be deleted and we would also suggest that "usually will" is replaced by "may" in the first sentence. It is not always possible to weigh the risks and burdens of assisted hydration and nutrition with the degree of certainty suggested in paragraph 93.

93. Where a patient's death is imminent and nutrition and hydration are already **being provided**, but the burdens outweigh the possible benefits to the patient, it **may be** appropriate to stop them.

Q26. 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?

No

Where the patient is imminently dying within hours or days, the provision of hydration and nutrition may no longer be relevant to sustaining life and relieving symptoms of patients in the terminal phase of their disease. The provision of tube feeding might also be regarded as unduly burdensome and intrusive.

The GMC guidance needs to be clear that the purpose of providing hydration and nutrition to a patient is to meet ordinary physiological requirements. It is also essential to make clear that hydration will not be deliberately withdrawn from those who are not dying in order to bring about death through dehydration.

We agree with the statement of Professor Craeme Catto in July 2005 after the Burke judgment in which he said:

"Our guidance makes it clear that patients should never be discriminated against on the grounds of disability. And we have always said that causing patients to die from starvation and dehydration is absolutely unacceptable practice and unlawful.... Today the court has reinforced our position."

Q27. Do you think that the guidance would apply in these circumstances?

No

Hydration and nutrition are necessary to sustain life in all living beings. This is true both in health and in sickness. Unless the disease is malnutrition or dehydration, or the patient has special dietary requirements e.g. a gluten free diet for coeliac patients, the provision of hydration and nutrition is ordinary care not medical treatment. In the case of new born baby with a very poor prognosis, the provision of hydration is not a treatment for the underlying condition, nor is the hydration making the patient's life intolerable but rather the underlying illness.

We believe these four elements are required for ethical decision-making namely a competent *clinical assessment* of the patient's condition and circumstances, clarification of both the *purpose* of and *intention* behind the proposed treatment and informed *consent* from the patient or their representatives. It should be no part of medical decision-making to cause the death of the patient. Foresight is not necessarily the same as intention. For example, it might be foreseen that the baby will die without ventilation but this should not be the intention for not providing intensive care. Parents who could not bear to see their baby to end its life on a ventilator on ITU are not directly intending the death of their child. However, it would be difficult to escape this conclusion if the parents authorised the dehydration of a disabled baby knowing that death through dehydration would inevitably follow.

We have therefore suggested the following changes to paragraph 91. The situation regarding neonates, children and young people have been dealt with in paragraphs 74 to 82.

91. Where a patient's death is not imminent (expected within hours or days) there remains a strong presumption in favour of providing assisted nutrition and hydration. In deciding the patient's 'best interests', the Mental Capacity Act requires that you and others involved in the decision-making must not be motivated by a desire to bring about the patient's death. Where the patient has previously indicated a desire to receive assisted hydration and nutrition, they normally ought to be provided. **Lord Phillips in *Burke*, expressly considered the situation of "the competent patient who regardless of the pain, suffering or indignity of his condition, makes it plain that he wishes to be kept alive". He held that: "No authority lends the slightest countenance to the suggestion that the duty on the doctors to take reasonable steps to keep the patient alive in such circumstances may not persist. Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder". (Para 34).**

Q28. Can you suggest any other situations where this guidance would apply?

No

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

Yes.

It should not normally be a problem for patients in a hospital setting where the relevant consultant ought to be available. In addition, it is very rarely the case that a second opinion cannot be obtained. In Scotland, where there are disagreements between the doctors and welfare attorney, there should be recourse to a second opinion doctor, listed on a register held by the Mental Welfare Commission, prior to referral to the Court of Session for a decision.

Cardiopulmonary resuscitation (paragraphs 98-112)

Q30. Do you agree that the guidance in this section achieves this balance?

Yes

The issue of CPR is often difficult. However in the overwhelming majority of cases it is associated with a very high mortality rate, is invasive and may be very distressing in the agonal stages of life. It is clearly not appropriate in many cases when a cardiac arrest is the final event in terminal illness.

CPR is the only common treatment which is discussed with patients in order that it is not given. Most treatments are discussed with patients in order to obtain consent for treatment. CPR may be a genuine treatment option in e.g. cardiac surgery or be required in the course of another procedure e.g. cardiac catheterisation, insertion of a pacemaker or during electrophysiological studies. Where defibrillation is not immediately available, e.g. in a coronary care unit, Casualty department or operating theatre, CPR is unlikely to be successful. The greater emphasis within the draft guidance that CPR need not be discussed in every case, particularly when it would be either intrusive or unnecessary, is to be welcomed. In the context of palliative care for example, a general discussion of the patient's needs in the final stages of life may be sufficient. Indeed, to introduce into such a discussion the question of CPR only to dismiss it may be particularly insensitive and unnecessary.

Q31. Do you agree this is the right approach to dealing with these situations? Please tell us why you agree or disagree.

Yes

CPR tends to be an all or nothing phenomenon. It might be appropriate also to consider the issue of a limited attempt at resuscitation e.g. defibrillation but not intubation and mechanical ventilation.

Working in teams

Q32. 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

As has already been pointed out in the guidance, relatives may be very disturbed about the withdrawal of hydration and nutrition. They may rightly see this as a form of abandonment of the patient and have real concerns that the death of the patient has been hastened by dehydration. The issues may not be fully apparent at the time when the relatives may be too close to the patient, emotionally numbed by the experience of coping with severe life-threatening disease and wearied though lack of sleep. Concerns about care at the end of the patient's life may not become fully apparent for months or even years. Where complaints have been made and the nursing and medical records have come to light, relatives may see opinions expressed about their reaction to their relative's illness and their own attitudes and beliefs that may cause them distress. Relatives may feel that they were not fully informed or involved in decisions or that the decisions had largely been taken out of their hands by the healthcare professionals acting in the patient's best interests. In the case of children, the case may be referred to the Court and decisions made that may conflict with the parents views e.g. in the case of the Conjoined twins 'Mary' and 'Jodie'.

Parents and relatives may also be disturbed at the use of sedation. In the case of David Glass, who had severe cerebral palsy, opiates were administered after coming off a ventilator against the wishes of his mother. David was taken from the hospital by his family. The European Court of Human Rights considered that the decision to impose treatment on David in defiance of his mother's objections gave rise to an interference with his right to respect for his private life, and in particular his right to physical integrity under Article 8 of the ECHR. It is therefore important that the views of parents are properly taken into consideration. A failure to do so might infringe the Article 8 rights of the child.

General Questions

Q33. 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?

Yes

The Catholic Medical Association, formerly the Guild of Catholic Doctors, and the Christian Medical Fellowship (CMF) have websites on which the ethical issues surrounding the care at the end of life are regularly reviewed.

Supporting materials

Q34. Are there any particular issues in the guidance that you would like to see covered in these additional materials?

Not sure

Impact on existing practice

Q35. 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).

Not sure

There are currently moves within Parliament to introduce support for, or even compliance with, physician assisted suicide. There are three amendments to the Coroner's and Justice Bill, which if enacted would permit doctors to certify patients as competent for "physician assisted suicide" (PAS) abroad. These amendments seek to decriminalise those who assist patients who travel to Zurich for euthanasia or assisted suicide. A far greater impact on practice in relation to end-of-life issues would occur in the event of legalisation of such practices in this country. The American Medical Association has persistently regarded as unethical the certification of subjects on death row as being mentally competent for execution. Hence, it is possible for the profession to regard it as unethical to support practices such as capital punishment which are nevertheless lawful. The GMC must respect the conscience of doctors and not render conscientious objection punishable. The fact that a procedure is legal is not sufficient to impose a duty to provide it upon either the profession as a whole or individual physicians.

It is therefore important that the GMC respect the rights of doctors to act with integrity in their profession according to both their professional competence and conscience. Should PAS and euthanasia become legal, the rights of conscientious objection will be all the more important. Since the majority of doctors are currently opposed to euthanasia and PAS, such practices can hardly be dismissed as ‘personal beliefs’.

Impact on equalities and human rights

Q36. 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?

No

In our response we have indicated that the guidance may infringe Article 2 (“right to life”); Article 3 (“freedom from inhumane and degrading treatment”); Article 8 (“right to private and family life”) in relation to the care of patients. Articles 10 (“right to freedom of expression”) and 11 (“freedom of assembly and association”) are also important in relations to conscientious objection. Article 6 (“right to a fair trial”) could also be invoked if there was disciplinary action against a doctor on grounds of conscientious objection. Religious discrimination issues (and conscientious objection) are dealt with under Article 9 as well as domestic law in the Equality Act 2006 and various aspects of employment law including Employment Equality (Religion or Belief) Regulations 2003 (Reg 3).

Q37. 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)

Yes

As always, those who are well educated and supported will do better than those who are socially isolated and either less able to articulate their own wishes or do not have representatives to put their case. Those with disability and mental incapacity are particularly vulnerable as the David Glass and Leslie Burke cases have illustrated. Moreover, when things go wrong the elderly, disabled and those with impaired cognitive ability will be less able to complain.

And finally

Q38. 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

- (A) We are sending separately an outline of the underlying ethical principles regarding the withholding and withdrawing of treatment and conscientious objection from a Catholic perspective.
- (B) We believe that it is important to distinguish care from medical treatment and that this would simplify the issues surrounding the withdrawal of hydration and nutrition. It would also help to put more emphasis on the intention behind treatment/non-treatment as this is an important part of medical decision-making. For example, we do not believe that hydration should be withdrawn from a non-dying patient with the intention or purpose of causing death through dehydration. It might be appropriate to state the basic principles underlying the document. Since many of the issues are difficult and/or contentious we do not think that the GMC guidance should be overly proscriptive. We certainly do not think that conscientious objection should be punishable. Whilst we agree with the approach to CPR, this section might perhaps be shortened.
- (C) Medical ethics deals with situations which cannot all be dealt with in GMC guidance. The purpose of the GMC is both to protect patients and to regulate the professional behaviour of doctors. It ought to be made clear which parts of the guidance should underscore good clinical practice and which aspects, if contravened, might form the basis for claims of professional misconduct and disciplinary proceedings. The guidance states that ‘must’ refers to matters of fundamental principle. In the document ‘must’ was used over 50 times and ‘should’ over 120 times. Since ‘must’ is used to signify an overriding duty or principle, there is ample scope for complaints from dissatisfied patients applying this guidance! Several of our members have commented on the length of the document. We have also suggested how the document may be shortened in parts, especially where there are difficult or contentious issues. These might best be addressed through developments in clinical practice rather than prescribing professional behaviour in an overly restrictive manner.

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

Yes

The GMC has clearly consulted widely on this issue over a 3 month period in a most comprehensive way. This is most welcome. We hope that responses to the consultation will be published.

We would be very happy to clarify any aspects of our submission or to provide any additional information on request. The submission will be published on the Catholic Union website in due course.

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Chairman of the Joint Medical Ethics Committee of the Catholic Medical Association and the Catholic Union of Great Britain.

PART II. SUMMARY OF SUGGESTED CHANGES TO NUMBERED PARAGRAPHS.

Suggested changes to numbered paragraphs. (**Changes in bold**)

About the guidance

1. Good care **towards the end of life** helps patients to live as well as possible until they die, and to die with dignity. This guidance is intended to support doctors' decision-making and help them to provide patients with high quality **palliative care**, including involvement of and support for those close to the patient (family members, carers and others who have an interest in their welfare). Providing this care means facing decisions which may be clinically complex and emotionally distressing and the guidance explores how doctors can address these issues.

3. This guidance is based on long-established ethical principles, which include doctors' obligations to show respect for human life; protect the health of their patients; and to make the **wellbeing** of their patients their first concern.

5. This guidance is addressed to doctors. However, it may help patients and the public understand what to expect of their doctors, in circumstances where patients and those close to them may be particularly vulnerable and in need of support. Members of the healthcare team may also benefit from this guidance, given their crucial role in delivering **good quality palliative care**.

How the guidance affects you

8. Serious or persistent failure to **take into account** this guidance **could** put your registration at risk. You must, therefore, be prepared to explain and justify your actions.

Introduction

9. Suggest delete.

10. **Palliative care**, which focuses on managing pain and other distressing symptoms, providing psychological, social and spiritual support to patients, and supporting those close to the patient. Palliative care can be provided at any stage in the progression of a patient's illness, not only in the last days of a patient's life when the focus of treatment has generally moved from trying to actively manage disease and prevent deterioration to managing the patient's symptoms and keeping them comfortable.

11. The most difficult and sensitive decisions in end of life care are often those around starting, or stopping, potentially life-prolonging treatments such as cardiopulmonary resuscitation (CPR), renal dialysis and mechanical ventilation. These treatments have many potential benefits including extending the lives of patients who otherwise might die from their underlying condition. The benefits, burdens and risks of these treatments are not always well understood and concerns can arise about over- or under- treatment, particularly where there is uncertainty about the clinical effect of a treatment on the individual patient, or about how the benefits and burdens for that patient are being assessed. Doctors and others involved

in the decision-making process may also be unclear about what is legally and ethically permissible, especially in relation to decisions to stop a potentially life-prolonging treatment.

12. The framework for decision-making in **palliative care** is essentially the same as for any other phase of clinical care. The principles of good decision-making are set out in *Consent: patients and doctors making decisions together*, which also provides advice about how to communicate effectively, and work towards achieving a consensus, with patients and those close to them and within the healthcare team. This guidance expands on *Consent*, explaining how the principles apply to specific issues that arise in relation to end of life care, which doctors, patients and others involved in making decisions can find difficult to address.

Equalities and human rights

14. Some patients (such as older people, those with disabilities, or from ethnic minorities) experience problems in accessing good quality care, and this may have serious consequences when they are in need of **palliative care**. Equalities, capacity and human rights laws reinforce the ethical duty on doctors to ensure that all patients receive the same standard of care.

Decision-making framework

Patients with capacity

17. Where patients have capacity to make decisions for themselves:

c. The patient weighs up the potential benefits, risks and burdens of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which one. They also have the **legal** right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all. **Nevertheless, where the patient either gives no reason, or irrational reasons, for the decision, the doctor may wish to ensure that the patient has understood the implications of treatment, is not under undue duress and that there is no lack of decision-making capacity.**

Addressing uncertainty

28 and 29. Suggest delete these paragraphs or significantly modify them.

Emotional difficulties in decision-making towards the end of life

30,31,32. Suggest delete these paragraphs.

Resource constraints

Suggest delete all but first sentence of paragraph 33.

33. Decisions about what treatment options can be offered may be complicated by resource constraints – for example, funding restrictions on certain treatments in the NHS, or lack of availability of intensive care beds.

Assessing the overall benefits of treatment options

37. You must not start or continue with a potentially life-prolonging **medical** treatment if the patient with capacity has refused it, and should not normally do so where the patient lacks capacity to decide and it is agreed that **such** treatment would not be of overall benefit to them. It may also be of no overall benefit to provide potentially life-prolonging treatments in the last days of a patient's life when the focus of care is changing from active treatment to palliation of symptoms and relief of the patient's suffering. **There should however, be a strong presumption in favour of the provision of hydration and nutrition.**

41. You must be careful not to rely on your personal views about a patient's quality of life or make judgements based on poorly informed or negative views about the healthcare needs of particular groups, such as older people and those with disabilities. **It should not be part of a doctor's role to decide whether a patient's life is worth living and such judgments should never form part of the rationale for treatment.**

Making advance requests for treatment

51. In planning ahead, some patients worry that they will be unreasonably denied certain interventions towards the end of their life, and so they may wish to make an advance request for those treatments. Some patients who are approaching the last days of life may have specific reasons for wanting to receive a treatment which has some prospects of prolonging their life, even if only for a very short time. **Some patients may hold strong views about receiving assisted nutrition and hydration towards the end of their life, because they see these not as medical treatment but as part of basic care.**

Making advance refusals of treatment

55. Where death is imminent (within a few days or within hours), and the burdens of continuing a potentially life-prolonging treatment outweigh any possible benefits to the patient, it usually **may** be appropriate to stop the treatment, while focusing on meeting the patient's needs for palliative care and effective symptom management. Where a patient has previously requested that the treatment be continued **in the event of mental incapacity, there remains a presumption in favour of giving it. However, the Courts have accepted that where life involves an extreme degree of pain, discomfort or indignity to a patient, who is sentient but not competent and who has manifested no wish to be kept alive, the circumstances may absolve the doctors of the positive duty to keep the patient alive. Where ANH is necessary to sustain life, the duty of care will normally require the doctors to provide it. Indeed, according to Lord Phillips in *Burke*, a deliberate failure to provide ANH in the face of a competent patient's wish to receive it, with the intention of causing the patient's death "would leave the doctor with no answer to a charge of murder."**If significant disagreement arises between you and the patient's representative or those close to them, or members of the healthcare team, about what would be of overall benefit to the patient, you must take steps to resolve this (see paragraphs 77-78 of *Consent: patients and doctors making decisions together* for guidance on resolving disagreements).

58. Advance refusals of treatment may not come to light until a patient has lost capacity. However, advance refusals which refer to the cessation of life-sustaining treatment must be in writing, signed and witnessed. If the witness is a doctor (s)he must ensure that

that patient not only has mental capacity but understands the implications of non-treatment. Whilst there is no legal requirement to discuss advance refusals with medical professionals, a failure to do so might raise questions as to their validity and applicability at a later date.

59. In deciding whether the advance refusal of treatment is clearly applicable to the circumstances that have arisen, you should check whether the advance refusal specifies particular treatments or circumstances when the refusal should apply. You should consider how long ago the decision was made; **the contents of any discussions with healthcare professionals and the degree of understanding of the relevant treatments when the refusal was made;** whether it has been reviewed or updated; any relevant **therapeutic developments** or changes in the patient's personal circumstances since the decision was made; any more recent actions or decisions of the patient that indicate they may have changed their mind. **An advance decision is not applicable to the treatment in question if there are reasonable grounds for believing that circumstances exist which the patient did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.**

60. According to the Mental Capacity Act, a person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment. If there is doubt or disagreement about the validity or applicability of an advance refusal of treatment you should make further enquiries, where time permits, and seek a ruling from the court where necessary. **However whilst a court ruling is sought, treatment that the doctor reasonably believes is necessary ought to be continued to prevent a deterioration in the patient's condition.** In an emergency, where there is no time to investigate further, the presumption should be in favour of providing treatment, if it has a realistic chance of prolonging the patient's life.

Recording and communicating decisions

62. Disagreements may arise regarding the withholding and withdrawing of care and treatment which may give rise to future complaints. You must make a record of the decisions made about a patient's treatment and care, and who was consulted in relation to those decisions. **Where complaints have arisen the contemporaneous record of any disagreements and the way they were resolved may be taken as evidence in deciding whether or not the doctor had acted reasonably and in the 'best interests' of the patient.**

Conscientious objections

67. The GMC, BMA and Mental Capacity Act Code of Practice recognise the right of doctors to conscientious objection regarding the withholding or withdrawing of life-sustaining treatment. There may rarely be occasions when you disagree with a patient's decision to refuse life-prolonging treatment, or to a refusal of treatment by his or her legal representative (donee of lasting power of attorney or welfare attorney). Under such circumstances you should make every effort to resolve such disagreements informally. In Scotland, you may refer to a second opinion doctor where the welfare attorney has refused to consent to treatment. In England and Wales, it may be necessary to refer unresolved disagreements to the Court of Protection. The Court of

Protection has powers to allow the transfer of the patient to the care of another doctor. Life-sustaining treatment ought to be provided to ensure that there is no deterioration in the patient's condition whilst a ruling is being sought from the Court. In those rare instances when it may be necessary to exercise your right of conscientious objection and to withdraw from the patient's clinical care, it is important to ensure that the wellbeing of the patient does not suffer in any way while another doctor takes over your role.

Assisted nutrition and hydration

84. Where patients are unable to take sufficient nutrition and/or hydration by mouth, even with support, you must carry out an assessment of their condition and their individual requirements for nutrition and/or hydration³³. You must consider what forms of assisted nutrition or hydration may be required to meet their needs. **It is also important to ensure that those with swallowing difficulties are also relieved of other distressing symptoms such as choking and the fear of aspiration, for example by adequate mouth care and oropharyngeal suctioning.**

85. Assisted nutrition and hydration includes a range of techniques from spoon or syringe feeding by mouth, intravenous or subcutaneous infusion of fluids (by 'drip'), nasogastric tube feeding, or administration of fluid and nutrients via a feeding tube placed through the abdominal wall either endoscopically (PEG) or radiologically (RIG). These techniques may prolong and significantly improve the quality of a patient's life. However, the range of techniques now available means that the problems and complications are usually minimal compared to the expected benefits. The appropriate technique can be tailored to the needs of the individual patient.

87. In the face of such uncertainties, concerns may arise about the possibility that a patient who is unconscious or semi-conscious, and whose wishes cannot be determined, might be experiencing distressing symptoms and complications or otherwise be suffering, because their needs for nutrition or hydration are not being met. Alternatively there may be concerns that attempts to meet a patient's perceived needs for nutrition or hydration may cause them avoidable suffering towards the end of their life. In some cases, patients and those close to them, or members of the healthcare team, may have strong beliefs that assisted nutrition and hydration are not medical treatments but part of basic nurture for the patient and should always be provided. **Relatives may also have concerns where it appears that assisted nutrition and hydration has been withdrawn in order to bring about the death of the patient because of a perceived view of the patient's quality of life.**

88. In view of these concerns, it is essential that you base your decisions on up to date clinical evidence or other authoritative guidance. As the benefits and burdens are different for assisted nutrition and hydration, you must assess these separately and seek a second opinion or expert advice if you are uncertain about them. In deciding which of the options for providing nutrition or hydration would be likely to meet a patient’s assessed need, you must ensure that the patient, the health care team, and those close to the patient (where the patient lacks capacity to decide), are fully involved in the decision. You should take steps to help those participating in the decision-making to understand your assessment of the patient’s needs, and any uncertainties underlying the options you consider would meet those needs. You should reassure them that, whatever your decisions about providing clinically assisted nutrition or hydration, you will assess the patient for the presence of distressing symptoms, for example signs of pain, breathing difficulties, confusion, and dry mouth and provide relief.

Hydration and nutrition must not be withdrawn or withheld with the intention of causing the patient’s death and relatives should be reassured that the patient will not die through deliberate dehydration

Patients with capacity

89. 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. Following the framework in paragraph 17, you must explain to the patient the benefits, burdens, risks or complications associated with the treatments, so that they can make an informed decision about whether to accept the treatment. **Reinforcing the duty of doctors to provide such treatment, Lord Phillips stated in the case of *Burke*: “Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient’s expressed wish to be kept alive, with the intention of thereby terminating the patient’s life, would leave the doctor with no answer to a charge of murder”.**

90. The basic duty of care for patients admitted to hospital was outlined by Lord Phillips, in the case of *Burke*, in the Court of Appeal: “So far as ANH is concerned, there is no need to look far for the duty to provide this. Once a patient is accepted into a hospital, the medical staff come under a positive duty at common law to care for the patient. A fundamental aspect of this positive duty of care is a duty to take such steps as are reasonable to keep the patient alive. Where ANH is necessary to keep the patient alive, the duty of care will normally require the doctors to supply ANH”. If assisted nutrition or hydration might prolong the life of a patient who lacks capacity to decide, **there is therefore a strong presumption in law that such basic sustenance should be provided.** There is also a presumption that such sustenance would be clinically appropriate. **Lord Phillips (para 64) regarded it unlikely that ANH would be regarded as clinically inappropriate “as we have said, administering treatment that is necessary to keep a patient alive cannot be described as ‘clinically inappropriate”.**

91. Where a patient’s death is not imminent (expected within hours or days) there remains a strong presumption in favour of providing assisted nutrition and hydration. In deciding the patient’s ‘best interests’, the Mental Capacity Act requires that you and others involved in

the decision-making must not be motivated by a desire to bring about the patient's death. Where the patient has previously indicated a desire to receive assisted hydration and nutrition, they normally ought to be provided. **Lord Phillips in *Burke*, expressly considered the situation of “the competent patient who regardless of the pain, suffering or indignity of his condition, makes it plain that he wishes to be kept alive”. He held that: “No authority lends the slightest countenance to the suggestion that the duty on the doctors to take reasonable steps to keep the patient alive in such circumstances may not persist. Indeed, it seems to us that for a doctor deliberately to interrupt life-prolonging treatment in the face of a competent patient's expressed wish to be kept alive, with the intention of thereby terminating the patient's life, would leave the doctor with no answer to a charge of murder”.**

Suggested changes to paragraphs 92 and 93

Consider deleting paragraph 93 and perhaps modifying paragraph 92 as follows:

92. Where a **patient's death is imminent within** in a matter of hours or **a few days**, and you consider that nutrition or hydration will not prolong their life, it **may not be** appropriate to start **or continue tube feeding**. However, you should assess the need for nutrition or hydration separately. For example, fluids may still provide symptom relief when nutrition is no longer of any overall benefit to the patient.

If these changes were made to paragraph 92, paragraph 93 would become redundant. Otherwise we would suggest changes to paragraph 93 as follows:

93. Where a patient's death is imminent and nutrition and hydration are already **being provided**, but the burdens outweigh the possible benefits to the patient, it **may be** appropriate to stop them.

All patients

95. You must regularly review decisions about the provision of assisted nutrition and hydration to take account of any changes in the patient's condition and follow the guidance in paragraph 22 on symptom management. (Note: deleted 'clinically').

96. Suggest delete.

97. Where conflict arises about whether assisted nutrition or hydration should be provided and this cannot be resolved by informal discussion or independent review, you should seek legal advice on applying to the appropriate court or statutory body for a ruling (see paragraph 42).

Cardiopulmonary resuscitation

100. A decision about whether CPR should be attempted should be made only after careful consideration of all relevant factors. **There is no ethical or legal obligation to offer treatments that are considered futile or where the risks of harm far outweigh any possible benefit. Therefore where CPR may be clinically indicated e.g. on a coronary care unit or catheter laboratory, it should usually be discussed with the competent**

patient or with those close to those patients who lack capacity to decide. Relevant factors to be considered in deciding CPR include:

- a. The likely clinical outcome, including the likelihood of successfully re-starting the patient's heart and breathing for a sustained period, the level of recovery that can realistically be expected after successful CPR and whether cardio-respiratory arrest is likely to recur³⁷.
- b. The patient's known or ascertainable wishes, including any information about previously expressed views, feelings, beliefs and values.
- c. The patient's human rights, including the right to life and the right to be free from degrading treatment.
- d. The likelihood of the patient experiencing severe unmanageable pain or other distressing side effects as a result of successful CPR.
- e. The level of awareness the patient has of their existence and surroundings.

Discussions where CPR will not be successful

104. If a patient who lacks capacity has appointed a welfare attorney whose authority extends to making decisions about **life-sustaining treatment, including CPR, the welfare attorney may consent to, or refuse, CPR. However, under the Mental Capacity Act court appointed deputies, unlike donees of lasting power of attorney, are not empowered to make such decisions.**

PART III. ETHICAL ASPECTS OF WITHHOLDING AND WITHDRAWING LIFE-SUSTAINING TREATMENT AND CONSCIENTIOUS OBJECTION: A CATHOLIC PERSPECTIVE

Introduction

This submission seeks to explain the Catholic position regarding two fundamental issues raised by the draft GMC document on the withholding and withdrawing of life-sustaining treatment. The first issue is the distinction between medical treatment and care and the extent of the duty of care to patients. The second is the right of conscientious objection.

Right to life and duty of care.

Every human being has a unique dignity and intrinsic value from the first moment of existence and throughout life whatever his or her physical condition. All human beings have innate and inviolable rights. The first is the “fundamental and inalienable right to life”¹ which is the foundation of all other rights². While human life is an intrinsic good in itself, it also has instrumental value for the attainment of all other goods and values. Hence a fundamental duty of care is owed to all persons to provide basic sustenance and care, particularly to those who are especially vulnerable and are unable to fend for themselves. This is a normative judgment about the basic duties owed to others based on “the intrinsic value and dignity of every human being.”³

Healthcare professionals have a positive duty of care for their patients to promote human wellbeing. However, this positive duty is not absolute and does not require the use of all possible means of preserving life. There is no ethical obligation to pursue relentless therapy when death is clearly imminent. “When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.”⁴

Conversely, there is an absolute prohibition in the Judaeo-Christian tradition on deliberately taking innocent human life, by act or omission. Euthanasia is “an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated.”⁵ Thus euthanasia includes not only active ‘mercy killing’ but also the omission of treatment when the purpose of the omission is to kill the patient. Hence, the morality of euthanasia should be seen “in the intention of the will and in the methods used.”⁶

The distinction between basic care and medical treatment.

Care includes those things that are universally required in health and disease to promote human wellbeing e.g. the provision of sustenance, warmth, shelter, clothing, basic hygiene and human companionship. Hence, the provision of hydration and nutrition constitutes care, not medical treatment. Care addresses physiological and psychological needs rather than pathology. It does not usually require particular diagnostic or therapeutic expertise and can often be provided by carers or even patients themselves. It does not normally require formal

consent. Conversely treatment addresses pathology and usually requires special clinical expertise to assess and administer. Where the basic care involves the provision of hydration and nutrition, a failure to provide such sustenance will inevitably cause the death of the patient through dehydration or starvation. If the patient is not imminently dying within hours or a few days, the deliberate omission of such basic care without sufficient cause, counts as euthanasia, per se. There is therefore a very strong ethical presumption that basic care ought to be provided.

In his address to the Bishops of the United States on October 2nd 1998, Pope John Paul II made it clear that assisted nutrition and hydration are to be considered normal care and ordinary means for the preservation of life. “It is not acceptable to interrupt them or to withhold them, if from that decision the death of the patient will follow. This would be euthanasia by omission.”

The deliberate withdrawal of hydration from a patient will inevitably cause death through dehydration in less than two weeks, unless the patient is already imminently dying from some other cause within hours or days. Even when the patient is at risk of fluid overload due to cardiac or renal failure, there remains a need for some fluid.

“Medical treatment has as its end the maintenance or restoration of health: nutrition and fluids have as their end the support of life. Nutrition and hydration, whether provided in the usual way or with medical assistance, do not of themselves remedy underlying disease and are a normal expression of our solidarity with the helpless. The adoption of a pattern of care with the intention of ending life is contrary to Catholic teaching. Elderly and disabled people, some suffering from progressive diseases which may cloud their minds, must be assured that the care they receive will be adequate and in their best interests. Parliament must never endorse proposals which would endanger their lives or the care to which they are entitled”.⁷

Ordinary and extraordinary treatment.

Everyone has a duty to seek medical care which has a hope of providing reasonable benefit without undue risks or burdens. The traditional distinction in Catholic ethics is between ordinary⁸ or proportionate⁹ and extraordinary or disproportionate means¹⁰. Extraordinary means are those that cause an undue risk or burden to the patient, disproportionate costs or are clinically futile. However, the term futility refers to the treatment and not to the life of the patient. The categorisation of means as extraordinary depends upon a judgment made in the light of the patient’s condition and circumstances and the expected outcome from the treatment. As with any medical opinion, the distinction between what constitutes ordinary or extraordinary treatment is a matter of prudent and conscientious judgment after consultation with the patient and others involved in their care. A means considered ordinary or proportionate for other patients should not be considered extraordinary or disproportionate for severely impaired patients solely because of a judgment that their lives are not worth living.

Care of the dying

Catholic teaching provides that a person in the final stages of dying need not accept "forms of treatment that would only secure a precarious and burdensome prolongation of life," but should still receive "the normal care due to the sick person in similar cases."¹⁵ We should never intentionally cause death or abandon the dying person as though he or she were unworthy of our care and respect.

On the other hand, when imminent death is seen as inevitable it should be recognised and accepted. It is important to avoid the so-called "therapeutic tyranny," which consists "in the use of methods which are particularly exhausting and painful for the patient, condemning him in fact to an artificially prolonged agony."¹¹ This is contrary to the dignity of the dying person and to the moral obligation of accepting death and allowing it at last to take its course. "Death is an inevitable fact of human life":¹² it cannot be uselessly delayed, fleeing from it by every means.¹³ Patients and families should not be subjected to unnecessary burdens, ineffective treatments and indignities when death is approaching. There is a real and legitimate right of patients to die with human and Christian dignity which those caring for the dying should respect and safeguard whilst accepting the natural end of life. "There is a radical difference between "death dealing" and "consent to dying": the former is an act of suppressing life, the latter means accepting life until death"¹⁴.

Needless suffering should be relieved and the patient's quality of life should be enhanced in ways that respect the inherent sanctity of life¹⁵. Treatment may be refused because it would impose new and serious burdens or risks. However, this decision to avoid new burdens and risks must be distinguished from directly intending to end life in order to avoid the burden of living in a disabled state.

Euthanasia

Euthanasia is any "act or omission which, of itself or by intention, causes death in order to eliminate suffering".¹⁶ Any act or omission which deliberately brings about, or causes, the death of a patient is therefore gravely wrong and contrary to the dignity of the human person.¹⁷ However, "discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of "over-zealous" treatment. Here one does not will to cause death; one's inability to impede it is merely accepted."¹⁸ Even for altruistic reasons a patient should not directly intend his or her own death by malnutrition or dehydration.

Euthanasia is an attack on life which no one has a right to make or request. The medical profession is uniquely placed to promote and protect human life and to respect human dignity. Since the time of Hippocrates there has been an historic prohibition on intentional killing. "I will give no deadly drug to anyone, even though it is asked of me, nor will I counsel such" (Hippocratic Oath).

Withdrawal of hydration and nutrition.

Hydration and nutrition constitute ordinary means of sustaining life and therefore are care rather than treatment. "The administration of food and liquids, even artificially, is part of the normal treatment always due to the patient when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia"¹⁹. John Paul II also emphasised this in 1998: "Nutrition and hydration are to be considered as normal care and ordinary means for the preservation of life. It is not acceptable to interrupt them or to withhold them, if from that decision the death of the patient will follow. This would be euthanasia by omission."²⁰

The ethical requirement to provide hydration and nutrition extends to those in persistent vegetative state (PVS):

"The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of possible recovery. I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act. Its use, furthermore, should be considered, in principle, ordinary and proportionate, and as such morally obligatory, to the extent to which, and for as long as, it is shown to accomplish its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering."²¹

Death by starvation or dehydration is the only possible outcome of the withholding and withdrawing of hydration and nutrition, howsoever administered, unless the patient is imminently dying from the underlying disease. If done knowingly and deliberately the withdrawal of hydration and nutrition constitutes euthanasia by omission.²²

Conscientious objection

Conscience is a judgement of the reason whereby the moral quality of an act is determined²³. The Christian tradition recognises that the obligation to obey conscience may override legal obligations^{24 25}. Healthcare professionals have both a right and a duty to act in good faith according to what is judged to be clinically appropriate and ethically sound²⁶. Where doctors are expected, or even required, to participate in the deliberate taking of life, by act or omission, through the denial of ordinary treatment and care, there is a moral obligation not to cooperate in any way^{27 28}. The doctor-patient relationship is a life-trusting one and this is how it should remain. Euthanasia is a "crime" in which health care workers, who are always and only guardians of life, can in no way cooperate.²⁹

The question of conscientious objection to withholding and withdrawing of life sustaining care and treatment arises most importantly when stopping the hydration of those who are not imminently dying. Under such circumstances the patient will inevitably die from dehydration within a matter of days, rather than from the underlying disease. This most commonly arises in stroke victims who are unable to swallow and are no longer able to make decisions for

themselves. The purpose and practical consequence of withdrawing sustenance from such patients is to deliberately cause their death because their 'quality of life' is judged to be unacceptable. It is not the provision of hydration and nutrition that is deemed to be ³⁰problematic so much as continued existence with the underlying condition.

Conscientious objection to the deliberate withdrawal of hydration and nutrition in order to cause the death of the patient will therefore create acute moral difficulty. The transfer of patients to others in order to bring about their death may be seen as hypocritical. Can it be right to ask another to do what you yourself find deeply wrong and offensive? To believe in something whilst acting in a completely different way, or to require another to do what you hold to be morally offensive, is a good definition of hypocrisy. Similarly, to deny the right of conscientious objection and to demand that physicians provide or assist in the provision of services or performance of procedures that they believe to be profoundly wrong is to treat them as means to their patients' ends and deprive them of their "essential humanity" as moral agents.

In our 2001 submission to the GMC, we stated:

"It is our position that hydration and nutrition should never be withdrawn as a means of deliberately bringing about the death of the patient. We hold that the practice of withdrawing hydration followed by "terminal sedation" to cause the death of a patient is totally unacceptable. No nurse or carer must ever be forced to participate in such a process, especially if they had expressed a conscientious objection to it. Doctors and nurses must not be placed in a situation of providing a standard of care which is indistinguishable from neglect. Where a doctor believes that an action, or withdrawal of treatment, is morally wrong, he may not in conscience ask someone else to perform that action/omission which he himself believes to be wrong. However, it would be right for that person to make their position clear, and then the patient, relative or carer, could seek other opinions. The onus of seeking other opinions should not lie with the individual expressing a conscientious objection".

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- ¹² John Paul II, *To two work groups set up by the Pontifical Academy of Sciences*, Oct. 21, 1985, in *Insegnamenti VIII/2*, p. 1082, n. 5.
- ¹³ Cong. Doct. Faith, *Declaration on Euthanasia*, May 5, 1980, in *AAS* 72 (1980) p. 549.
- ¹⁴ Charter for Health Care Workers. Pontifical Council for Pastoral Assistance. Paragraph 148. <http://www.consciencelaws.org/Examining-Conscience-Ethical/Ethical29c.html>
- ¹⁵ “Quality of life must be sought, in so far as it is possible, by proportionate and appropriate treatment, but it presupposes life and the right to life for everyone, without discrimination and abandonment.” Pope John Paul II, Address of April 14, 1988 to the Eleventh European Congress of Perinatal Medicine: *AAS*, Vol. 80 (1988), p. 1426
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- ¹⁷ Catechism of the Catholic Church. Para 2277. <http://www.vatican.va/archive/ccc>
- ¹⁸ Catechism of the Catholic Church. Para 2278. <http://www.vatican.va/archive/ccc>
- ¹⁹ Charter for health care workers. Pontifical Council for Pastoral Assistance (paragraph 120).
- ²⁰ Address of Pope John Paul II to a group of bishops from the United States of America on a visit “ad limina” on 2nd October 1998.

²¹ Address of John Paul II at an international congress on “life-sustaining Treatments and the Vegetative State: Scientific Progress and Ethical Dilemmas.” March 20th 2004

²² Ibid.

²³ “Conscience is a judgment of reason by which the human person recognizes the moral quality of a concrete act”. Catechism of the Catholic Church. Paragraph 1796.

²⁴ “The citizen is obliged in conscience not to follow the directives of civil authorities when they are contrary to the demands of the moral order, to the fundamental rights of persons or the teachings of the Gospel. *Refusing obedience* to civil authorities, when their demands are contrary to those of an upright conscience, finds its justification in the distinction between serving God and serving the political community. "Render therefore to Caesar the things that are Caesar's, and to God the things that are God's."(*Mt* 22:21.) "We must obey God rather than men" *Acts* 5:29.)” Catechism of the Catholic Church. Paragraph 2242.

²⁵ “Authority is exercised legitimately only when it seeks the common good of the group concerned and if it employs morally licit means to attain it. If rulers were to enact unjust laws or take measures contrary to the moral order, such arrangements would not be binding in conscience. In such a case, “authority breaks down completely and results in shameful abuse." (John XXIII *PT* 51)”Catechism of the Catholic Church. Paragraph 1903.

²⁶ “Man has the right to act in conscience and in freedom so as personally to make moral decisions. "He must not be forced to act contrary to his conscience. Nor must he be prevented from acting according to his conscience, especially in religious matters."(*DH* 3 § 2)”. Catechism of the Catholic Church. Paragraph 2272.

²⁷ “Medical and paramedical personnel—faithful to the task of "always being at the service of life and assisting it to the end" cannot cooperate in any euthanistic practice even at the request of the one concerned, and much less at the request of the relatives. In fact, the individual does not have the right to euthanasia, because he does not have a right to dispose arbitrarily of his own life. Hence no health care worker can be the executive guardian of a non-existent right”. The Charter for Health Care Workers. Pontifical Council for Pastoral Assistance to Health Care Workers. 1995. Paragraph 148.

²⁸ “Citizens are obliged in conscience not to follow the directives of civil authorities when they are contrary to the demands of the moral order.”“We must obey God rather than men" (*Acts* 5:29). Catechism of the Catholic Church. Paragraph 2256

²⁹ John Paul II in an address to the Pontifical Academy of Sciences, October 21st 1985.