Changes to the Mental Capacity Act Code of Practice and implementation of the Liberty Protection Safeguards (LPS)

This response is submitted by the Christian Medical Fellowship (CMF). CMF has about 5,000 UK members, most of whom are doctors working in a wide range of clinical settings. The membership also includes medical students, nurses and midwives. We seek to equip Christian healthcare professionals to live and work for Jesus Christ.

Introduction

We wish to thank the Department of Health and Social Care, the Ministry of Justice, and the Department for Education, for their work in producing these draft proposals. Reform of the complex Deprivation of Liberty Safeguards (DoLS) has been long awaited and is much appreciated. The decision to merge the LPS guidance into the Mental Capacity Act 2005 (MCA) Code we also commend and trust that the new LPS scheme will truly reflect the principles of the MCA as a result.

We regret the consultation's failure to highlight changes to, or provide links to, previous wording for ease of comparison. We accept that this does not represent a change to normal government practice but would argue that the complexity of this consultation deserves a departure from normal practice. It has been an excessively time-consuming process to review the changes to the Code. More helpful documentation would encourage greater engagement in the consultation.

CMF's response is mainly to issues covered by Chapter 5.

Chapter 5: 'Best interests' decisions.

We welcome many of the proposed changes that amend the Code in the light of recent legal cases, and those that emphasise that best interests must be understood, as far as is humanly possible, **from the patient's perspective,** and not assumed to align with how a clinician thinks he or she would feel in the patient's shoes.

a) Enabling capacity

We propose that 'all reasonable efforts' to determine the wishes of the person lacking capacity **specifically include the withdrawal of sedation**, allowing the patient opportunity to regain such consciousness as they can and to assess the degree to which they can contribute meaningfully to the decision-making process.

In this connection we cite the case of *Barnsley Hospital NHS Foundation Trust v MSP* [2020].[1] A man with a history of mental health issues and chronic gastrointestinal disease made clear to his family (and in an unwitnessed 'advance decision') his wish not to live with an ileostomy. Years later, in pain

[1] Barnsley Hospital NHS Foundation Trust v MSP [2020] EWCOP 26

and sepsis, and facing the need for urgent surgery that could leave him with a permanent stoma, he gave informed consent to the operation. The surgeon was unaware of the 'advance decision' and took the patient's consent at face value. When the patient's advance decision was made known by his family following surgery, and with the patient still sedated and on post-operative pain relief, the hospital referred the case to the Court of Protection. The judge had to decide whether to honour the unwitnessed advance decision document or interpret consent to surgery as a change of mind by the patient. A third option, for the patient to be weaned off sedation and analgesia post-operatively until he could make his wishes known, appears not to have been included (though full clinical details are not available to us).

In the event, the judge ruled that the patient's best interests would be served by keeping him deeply sedated and withdrawing clinically administered nutrition and hydration (CANH). MSP was not terminally ill. He lacked capacity only because he continued to receive heavy sedation following surgery. It appears that what took place was essentially euthanasia by omission (of CANH) and increasing terminal sedation. MSP was 'made' to die and did so within a few days.

We accept that this was a complex case, but it nonetheless appears to fall short of the standards set out in the 2005 MCA (paras 5.13 and 5.25). The patient was clinically stable, following surgery. The underlying condition was not life-limiting. It was reasonable to assume MSP would regain sufficient awareness within days to be able to affirm his own wishes, one way or the other.

In 5.44-48, therefore, we contend that where a person lacks capacity to make a decision solely as a result of sedation, the obligation under s1(3) to take 'all practicable steps' to enable the person to make their own decision includes bringing that person out of sedation, at least temporarily.

We would also like to suggest that the case above (*Barnsley Hospital NHS Foundation Trust v MSP* [2020]) be anonymised and used as the basis for a Scenario in the new version of the Code.

b) Ensuring safety

Following the Supreme Court's 2018 judgement in the case of *An NHS Trust vs Y*,[2] such decisions should be made at local level without reference to the courts, except in cases where there is unresolvable disagreement. Their Lordships ruled that compliance with Art. 2 of the ECHR is dependent on the existence and practical application of a regulatory framework, such as that provided by the British Medical Association's (BMA's) guidance (and endorsed by the General Medical Council).[3]

The BMA guidance called for a national register of patients in prolonged disorders of consciousness (PDOC) to be created, and for the regular audit of deaths, following the withholding or withdrawal of CANH, as part of internal governance and external regulatory review procedures. This was to ensure that 'best interests' decisions were being made in line with the MCA and good practice guidance. Internal audit would be the responsibility of NHS Trusts and Clinical Commissioning Groups, and external review and audit would be carried out by organisations such as the Care Quality Commission and the Health Inspectorate of Wales.

[2] NHS Trust v Y [2018] UKSC 46

[3] BMA 2018: 'Clinically assisted nutrition and hydration (CANH) and adults who lack the capacity to consent' https://www.bma.org.uk/media/1161/bma-clinically-assisted-nutrition-hydration-canh-full-guidance.pdf

Two years after the publication of the BMA guidance, Freedom of Information requests were made by us between January and March 2020 to Acute and Specialist Hospital Trusts and CCGs in England. A total of 342 were approached, which represents 95% of providers, with an overall response rate of 88.8%. **The responses show that no Trust keeps a register of such deaths or has arrangements for auditing them.**[4] Moreover, the CQC in response to an FOI request also has stated that it does not require such information to be made available as part of its inspections.

The safety of the process to limit or withdraw CANH depends on external scrutiny. At present, such scrutiny is entirely lacking.

We strongly request that the accurate recording and internal audit of data relating to deaths following the withholding or withdrawal of CANH (and/or other life-sustaining treatment) from persons who lack capacity be made a <u>statutory</u> requirement for NHS Acute Trusts and CCGs in the revised MCA Code of Practice.

We further request that the revised Code place a <u>statutory</u> duty on the CQC/Health Inspectorate of Wales to provide external scrutiny of these processes.

These two requirements could be added as bullet points following para 5.108 in the draft Code of Practice.

c) Other recommendations

i) In footnote 42 to para. 5.55, we think it would be relevant to signpost the RCP's 2020 Guide *'Supporting people who have eating and drinking difficulties'*. For example, para. 4.2.2 of this Guide advises, "Oral nutrition support or CANH may help in symptom control (see chapters 2 and 3). If it does, that will be relevant to the question of whether it is in the patient's best interests to start, continue or withdraw it".

ii) At 5.57 (3rd bullet) Suggested citation: *Aintree Hospitals NHS Foundation Trust v James* [2013] UKSC 67, https://www.bailii.org/uk/cases/UKSC/2013/67.html, para. 44.

iii) Also, in 5.59 or footnote 43, as well as in 6.37-38 and 7.21-31, we suggest it is important to mention the need to have regard to any guidance issued by the Court of Protection, especially as this may change over time. Current guidance is at https://www.bailii.org/ew/cases/EWCOP/2020/2.html, paras. 8-9 being relevant to 5.59 of the Draft.

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[4] Absence of monitoring in withdrawal of clinically assisted nutrition and hydration (CANH) and other treatments: a cause for concern? Alice Gray, Mark Pickering and Stephen Sturman. *Clinical Medicine* 2021 Vol 21, No 3: 235–7