Mental Capacity Act 2006
Draft Code of Practice

Submission

to the

Consultation by the
Department of Constitutional Affairs

by

The Maranatha Community
in association with the
The Council for Health and Wholeness

June 2006

Submission

Mental Capacity Act 2005

Draft Code of Practice

Contents

1. PREFACE 3

2. INTRODUCTION 4

3. CHAPTER 4 – CONCEPT OF 'BEST INTERESTS'

QUESTION 4 (A) 5

4. CHAPTER 8 – ADVANCE DECISIONS

QUESTION 8 (A). 8

5. CONCLUSIONS 10

1. Preface

1.1 This Document

This document has been prepared in response to the Consultation by the Department for Constitutional Affairs – Mental Capacity Act 2005, Draft Code of Practice. The submission has been prepared by the Maranatha Community and the Council for Health and Wholeness. Representatives from both bodies would be happy to give oral evidence to the Committee.

The submission is addressed to Communications Team, Mental Capacity Implementation Programme , Department for Constitutional Affairs, 5th Floor, Steel House, 11 Tothill Street , London SW1H 9LH , Tel: 020 7210 0025/37 Fax: 020 7210 0007 , Email: makingdecisions@dca.gsi.gov.uk.

1.2 The Maranatha Community

The Maranatha Community is a Christian movement with many thousands of members throughout the country active in all the main churches. Its membership includes a substantial number of people involved in the health and caring professions and in a wide range of voluntary work. Since its formation 25 years ago, it has been closely involved in work with children and young people, those with drug and alcohol problems, and with the disabled and disadvantaged. Maranatha has taken the initiative in a broad range of projects directly contributing to the health of the nation and it also has extensive international experience. The Trust is a registered charity number 327627.

The Maranatha Community
102 Irlam Road, Flixton, Manchester M41 6JT Tel: 0161 748 4858 Fax: 0161 747 9192
Email: info@maranathacommunity.freeserve.co.uk; www.maranathacommunity.org.uk
The Leader of the Community is Mr. Dennis Wrigley.

1.3 The Council for Health and Wholeness

The Council is a multi-disciplinary body embracing doctors drawn from a variety of specialities, nurses and various medical auxiliaries, counsellors, chaplains and others. It has close links with the healing ministry of the Christian church and is involved in a broad range of research projects.
The Council for Health and Wholeness is based in the offices of the Maranatha Community. Its medical co-ordinators are Dr. Hans-Christian Raabe & Dr. Linda Stalley.

2. Introduction

2.1. The Maranatha Community and the Council for Health and Wholeness welcome the consultation by the Department for Constitutional Affairs concerning the 'Mental Capacity Act 2005' Draft code of practice.

2.2. We would like to acknowledge the care the Department for Constitutional Affairs has taken in listening to views of many stakeholders including offering to meet with representatives of many different organisations to clarify concerns.

2.3. We want to acknowledge the good intentions of those involved in drafting this legislation and the Code of Practice. However, we remain seriously concerned about several aspects of the Mental Capacity Act (MCA) and the Draft Code of Practice.

2.4. We would like to express our concern in general at the complexity of this legislation. The consequence of this complexity is that the Draft Code of Practice runs into over 170 pages. We believe it is quite unlikely that busy healthcare professionals will be able to read such a long document. It may therefore be advisable to produce summary sheets – perhaps just an A4 sheet each - with the essential information about certain aspects of the Act, for example on the section of capacity, lasting powers of attorney, advance decisions etc.

2.5. We would like to focus on the questions associated with Chapters 4 and 8 of the Consultation.

3. Chapter 4 – Concept of 'best interests' Question 4 (a)

3.1. While we obviously agree that – where a person lacks capacity – the Act allows people with power of attorney to make decisions on behalf of that person and that these decisions have to be made in that person's best interest, **we are not convinced that this section offers clear guidance on how to establish what is in a person's best interest**.

3.2. While we agree completely with the principles of *'equal consideration and non-discrimination'* (4.12-4.13), *'considering all relevant circumstances'* (4.14-4.17), *'regaining capacity'* (4.18-4.20), *'permitting and encouraging participation'* (4.21-23), *'special considerations for life-sustaining treatment'* (4.24-4.29) we are less convinced that the sections on *'the person's wishes and feelings, belief and values'* (4.30-4.41) are that helpful in this context.

3.3. We would especially commend the sentence in section 4.27 which clarifies that to **withdraw life-sustaining treatment with the intention of bringing about the person's death (= the definition of 'passive euthanasia') is prohibited:**
"However, there will be some limited number of cases, for example in the final stages of terminal illness, where treatment is futile or where there is no prospect of recovery. In such circumstances, it may be in the best interests of the patient to withdraw or withhold treatment. All the factors in the best interests checklist must be considered, but the person determining best interests <u>must not be motivated in any way by the desire to bring about the person's death</u>." [emphasis ours]

3.4. We would be grateful for an addition to be inserted into the code of practice, namely that, to **withdraw life-sustaining treatment with the intention of bringing about the person's death is a criminal offence.**

3.5. We would like to express the following serious **concerns about the section *'the person's wishes and feelings, belief and values'*** (4.30-4.41). This section states how to come to a conclusion on how to determine best interests, based on the subjective wishes, feelings, beliefs and values. In the absence of absolutes – such as health and life – this is very difficult and, in our opinion, impossible to achieve.

3.6. If the current 'non-absolute' criteria for determining 'best interests' in the Bill are applied to a **real case history** of a patient with severe depression and multiple suicide attempts who was incapacitated following an overdose, **one could easily come to the conclusion that it was in this patient's best interest not to be resuscitated.**

3.7. We have applied those suggested criteria to the following **real case history** of a patient with severe depression who – following an overdose – is incapacitated.

3.8. Case History:

3.8.1. A 38-year-old woman with longstanding mental health problems is admitted to hospital following a severe life-threatening overdose, probably with antidepressants. In the past, she has been given varied diagnoses such as bipolar disorder, depression, schizophrenia, "personality disorder" and alcoholism. She is very unwell and is not breathing sufficiently on her own. She has also

developed aspiration pneumonia. She would require active treatment, such as intubation and ventilation in intensive care (ITU) in order for her to survive.

3.8.2. She is unemployed and lives with a male friend, having been separated from her husband and having little contact with her daughter because of her illness. There is a past history of many suicide attempts by overdose, up to four per year. Three years ago, she suffered a cardiac arrest following an overdose with tricyclic antidepressants.
Because of her acute medical condition, pneumonia, respiratory depression and impaired consciousness due to the drugs and alcohol she has taken, her capacity to make decisions is severely impaired.

3.8.3. Fortunately, the MCA was not law when she took her last overdose. She made an excellent recovery following treatment and following adjustment of her medication and increasing counselling she is fairly well with a good quality of life.

3.9. Discussion

3.9.1. Following the principles of the MCA, treatment decisions have to be based on the assessment of this patient's best interests. According to the section 4.30, the following factors must be taken into account in trying to decide what may be in a person's best interest:

3.9.2. *'The person's past and present wishes and feelings'* (4.30 (a)) and *'the beliefs and values that would be likely to influence his decision if he had capacity'* (4.30 (b)) The only certain thing we have about this person at the time of admission is the history of many suicide attempts as documented in the old medical records which are available at the time of the admission. Following the previous psychiatric assessments, a diagnosis of depression/bipolar disorder and personality disorder was made on each occasion.
She has on several occasions in an objective manner expressed her wish to die. Would it therefore be appropriate to state that her *past and present wishes and feelings* are that she no longer wants to live and that therefore treatment aimed at saving her life should be withheld?

3.9.3. Obviously, the other sections, such as *'considering all relevant circumstances'* (4.14-4.17), *'regaining capacity'* (4.18-4.20), *'permitting and encouraging participation'* are relevant but may not be applicable, as it is unclear, whether the patient will regain consciousness before a decision on whether invasive treatment should be initiated can be made. **Once invasive treatment** (e.g. intubation, ventilation) **is initiated, any withdrawal of this treatment may lead to the patient's death** (cf. Bland case) **and therefore could be considered 'passive euthanasia' which is prohibited by the MCA.**

3.9.4. The section on *'The views of other people'* (Sections 4.42-4.46) is probably not helpful. The closest contact is her male friend. He is a poor historian and asked about her mental state can only say that she hasn't been too well recently. Obviously, he is very upset at her taking an overdose and wants to know whether she will be all right. She is estranged from her husband. At the time of admission, her usual GP is not available.

3.10. Using the **criteria of the MCA for best interests, one could easily come to the conclusion, that in this situation, death would be in the 'best interest' of the patient.** Obviously, the subsequent developments proved that this was definitely not the case. If the MCA had based the definition of 'best interest' using absolute criteria such as aiming to, where possible, preserve life and restore health, the patient's best interests would be far safer and less complicated to establish.

3.11. We note the many sections, 4.53 through 4.61, show that the process of establishing best interests is at best cumbersome and at worst impossible, based on the subjective criteria used in the Act. Had absolute criteria – such as aiming to preserve life and restore health been used, this would have simplified matters dramatically for busy health professionals.

3.12. We would like to point out that this issue had been stated on several occasions to the DCA, for example in our submission to the leaflets on 'making decisions', the Joint Briefing on the then Mental Capacity Bill prepared jointly by the Lawyers Christian Fellowship and the Maranatha Community from October 2004, which was sent to all MPs and in a letter by Dr Raabe to Mrs Susan Johnson, Head of Incapacity Division, DCA, dated 11.01.2004.

4. Chapter 8 – Advance Decisions Question 8 (a).

4.1. We believe it is extremely problematic to enshrine Advance decisions (AD) into law and making them legally binding.

4.2. We are pleased that – as a safeguard – section 62 has been introduced into the MCA, as explained in paragraph 8.7*: ‘no one can ask for and be given unlawful procedures, such as assistance in committing suicide.’*

4.3. Section 8.15 states that:*‘Particular concerns about capacity may arise in relation to advance decisions made by people who have suicidal tendencies. A doctor faced with an advance decision made by someone who was clearly suicidal may raise questions as to whether the person had capacity to make the advance decision. If the doctor is not satisfied that an advance decision was made with capacity, or if there are doubts about its existence, validity or applicability (…treatment may be given without fear of liability)*

4.4. **This shows one of the main problems with AD: How does a doctor know for sure, that this decision was not made while the person had suicidal tendencies?** Research shows very clearly that individual patients change their mind regarding whether they want to live or die:

4.5. There are serious problems with Advance decisions (AD) to refuse treatment, none of which are adequately addressed by the Code of Practice:

4.6. **There are enormous practical problems with AD** :-

4.6.1. How does a doctor know for sure that the AD was not written under duress?

4.6.2. **How can a doctor be certain that the AD I have been given** (for example by relatives of the patient) **has not been revoked since?**

4.6.3. How does a doctor know that the patient has not changed his/her mind since the issue of the AD?

4.7. Section 8.41 refers to this scenario. However, it is essentially impossible for a treating doctor to know with certainty whether or not a patient has changed his mind since making an AD. In addition, research evidence shows that people do change their minds regarding decisions to do with treatment or refusal of treatment:

4.7.1. AIDS patients were asked about their preferences for cardiac resuscitation. One-quarter of AIDS patients who initially desired cardiac resuscitation had changed their minds four months later. **One-third of AIDS patients who initially declined cardiac resuscitation stated on the second interview that they would accept it now.** Patients reporting changes in physical function, pain, or suicide ideation were more likely to modify their desires to be resuscitated. (Weissman JS et al. The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. Med Decis Making. 1999; 19 :16-26.)

4.7.2. In a survey of terminally ill patients, a total of 60% supported euthanasia in a hypothetical situation, however only 10.6% reported seriously considering

euthanasia for themselves. A factor associated with being less likely to request euthanasia was feeling appreciated, factors associated with being more likely to request euthanasia were depression, significant care needs and pain. At follow-up interview **two to six months later, half of all terminally ill patients who had considered euthanasia for themselves changed their minds**, while an almost equal number began considering these interventions. (Emanuel EJ et al. Attitudes and desires related to euthanasia and physician-assisted suicide among terminally ill patients and their caregivers. JAMA 2000; 284: 2460-8.)

4.7.3. In Oregon, **nearly one in two patients who initially requested physician-assisted suicide changed their mind after initiation of treatment, such as pain control, prescription of antidepressant medication or a referral to a hospice**. However, among those patients, where no active symptom control was initiated, only 15% of those who initially requested physician-assisted suicide changed their mind. (Ganzini L et al. Physicians' experiences with the Oregon Death with Dignity Act. New England Journal of Medicine 2000; 342: 557-63.)

4.8. It will be impossible for patients in advance to anticipate the result of an AD. For example the 'Living Will' from the organisation Exit states that antibiotics should not be given. However, a patient with a stroke developing a pneumonia or an elderly patient with a urinary tract infection may benefit from antibiotics, for example being less breathless or being less confused. This treatment would not be possible following the 'Living Will'.

4.9. The 'Living Will' of the Voluntary Euthanasia Society stipulates under the 'Schedule' that 'advanced disseminated malignant disease' would be one of the conditions, under which no treatment be given aimed at 'prolonging or sustaining' my life. However, certain conditions such as testicular cancer or some lymphomas would fall into this category and these respond very well to chemotherapy, so that patients can actually be cured of their malignancies. Would the doctor then have to let this patient die?

4.10. Advances in medical science may make an AD obsolete and patients might die of treatable conditions. If a disease, for example disseminated cancer, is to trigger the AD, it may be that at the time of the drafting of the AD this disease was not curable. However, with the advance of medical science, it may be treatable when the AD becomes relevant. The AD of the Voluntary Euthanasia Society stipulates that 'advanced disseminated malignant disease' would be one of the conditions, under which no treatment should be given aimed at 'prolonging or sustaining' a person's life. However, already today, some cancers or lymphomas fall into this category, but they respond very well to chemotherapy, so that patients can be cured. However, if AD became compulsory, a doctor might have to let patients die of treatable conditions.

4.11. The Bill claims that all artificial nutrition and hydration is medical treatment (para 8.22) Withdrawal of treatment therefore could mean withdrawal of nutrition and hydration. Patients will die of dehydration or starvation if the Bill became law in its current form. This amounts to 'passive' euthanasia.

4.12. The Bill will lead to euthanasia by the backdoor, since it creates a political and social climate, where withdrawal of treatment (including withdrawal of fluids and nutrition) following an AD is being seen as ***beneficial*** to the patient. However, it will not be long before we will hear calls to legalise euthanasia, since it will be considered much more humane to kill patients quickly (for example through a lethal injection), rather than letting them die slowly of thirst or hunger.

5. Conclusions

5.1 **The Government claims that the MCA is not about euthanasia. However, one wonders why the Voluntary Euthanasia Society has been among the most enthusiastic supporters of the Bill.**

5.2 In this context it is an anomaly in the Bill that the concealment of an AD is mentioned as a criminal offence, however not the concealment of a *revocation* of an AD.

5.3 We would like to point out that this issue had been stated on several occasions to the DCA, for example in our submission to the leaflets on 'making decisions', the Joint Briefing on the then Mental Capacity Bill prepared jointly by the Lawyers Christian Fellowship and the Maranatha Community from October 2004, which was sent to all MPs and in a letter by Dr Raabe to Mrs Susan Johnson, Head of Incapacity Division, DCA, dated 11.01.2004.

5.4 **For the above reasons, we believe that it is impossible to legislate with sufficient safeguards once AD have become legally binding.**

5.5 **In addition AD are open to abuse.** The elderly and disabled are particularly vulnerable and may feel pressure, whether real or imagined, to make an AD.
AD should remain only advisory.

5.6 **We remain unconvinced that there are sufficient safeguards in place surrounding the decision-making about life-sustaining treatment and AD.** Physicians will be placed in an invidious position for two reasons:

i. They will have to make the difficult assessment of whether an AD is applicable and valid and, as a result of this assessment, may withdraw treatment with the possible consequence of the death of a patient. **We can envisage the situation where a physician wrongly comes to the conclusion that an AD is applicable and valid and bases his decision on this wrong assumption, leading to the death of a patient who wanted to live.**

ii. **Conversely, a doctor may fear civil or criminal proceedings (see paragraph 8.4) if he applies treatment on the incorrect assumption that an AD to refuse life-sustaining treatment is not valid or applicable.**

5.7 Doctors will have to base their decisions on whether or not to withdraw even life-sustaining treatment on the basis of a document, an AD, **where the doctor cannot be sure whether it was written under duress, has been revoked since, has been superseded by medical advances or whether the patient has changed his or her mind.**

5.8 While we are pleased with the insertion of a conscientious objection clause (8.55-57), some **physicians will still be in the invidious position of having to withdraw nutrition and hydration by tube, thereby bringing about a very unpleasant death to the patient by dehydration or starvation.**

June 2006