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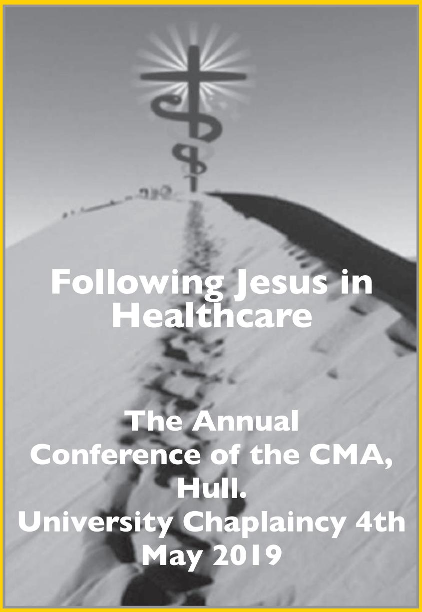

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JOURNAL OF THE CATHOLIC MEDICAL ASSOCIATION (UK)

WOULD YOU REFUSE A DYING MAN WATER? CONCERNS ABOUT THE WORKING OF THE MENTAL CAPACITY ACT

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Mental Capacity Act 2005

Code of Practice

An appeal

In this article we are appealing to members of the public to tell us where they have seen examples of the Mental Capacity Act working well for their loved ones, making things difficult for their loved ones, being used to provide excellent care, or being used to excuse poor care etc. Each section of this article therefore attempts to set out key areas of concern. We believe that we need to be able to discuss more widely and in greater depth the problems of the Mental Capacity Act. We need to know more about its problems and weaknesses as well as its strengths.

Introduction

The Mental Capacity Act [1] was introduced in 2005. At the time it was stated that it would "enable decision making for the mentally incapacitated". 15 years later, we believe that there are some real concerns with the way in which the MCA is working. In 2013 the House of Lords stated that Deprivation of Liberty (DoLS) legislation is "not fit for purpose" and yet reform of DoLS remains unachieved and elusive.

We believe that, in addition to the problems of DoLS, the MCA itself has real limitations and poses substantial risks for people who lack capacity. Those risks are even greater in people who not only lack capacity but who are also disabled, elderly, frail or who suffer from dementia etc. We worry that the MCA can easily be misused to deny care to such people or may be associated with poor care. We are concerned that the structure of the Act may predispose towards poor care and poor outcomes. An Act designed to protect the vulnerable may be doing exactly the opposite. It can be used to enable the withdrawal of the opposite. It can be used to enable the withdrawal of care, including nutrition and hydration from mentally incapacitated people and can be used to cause death by withdrawal of clinically -assisted nutrition and hydration. We are also concerned that the Act asks clinicians to think of alternatives to the best care even in situations such as personal care for incontinence etc. That requirement, along with the Act's requirement for clinicians to consider "less restrictive options" for care can push clinical care options towards riskier clinical practice and negligence.

We believe that the limitations of the Mental Capacity Act, need to be modified by good evidence-based clinical practice which benefits patients and their families.

But we also think that the evidence of the MCA doing harm needs to be collated so that it can become coherent. At present, while there are many reports and concerns about it, those reports are either newspaper articles or multiple anecdotes. We are therefore appealing for people to share with us their experiences of the MCA. We want to know more about its strengths and problems. Our key concerns and associated questions are set out below

1. There is an overarching concern that mentally incapacitated patients and their families/carers struggle to know what to say and how to say things to those providing care

Families repeatedly report worrying that the care they are seeing offered is unacceptable, but they dare not say anything because they are afraid that if they do the staff will "take it out" on their loved ones. Protecting very unwell and dying people at the moment of their greatest vulnerability and maximum dependence upon the mercy of others is very onerous. Taking action to protect your loved one may well make your loved one more vulnerable. There is a very strong imbalance of power, knowledge and (often) negotiating skills between families and healthcare staff.

Families really struggle to know how to protect and speak out for their loved ones. While this was clearly the case before the introduction of the MCA, it has not improved since 2005 and may be worse.

2. The healthy do not choose the same way as the sick

The Mental Capacity Act is deeply imbued with a set of assumptions that, while we are healthy, we can predict how we will be when we are unwell and how we will choose in those circumstances. An example would be advance refusals that require doctors to leave a patient untreated, or un-hydrated so that they will die. The way we thought about ourselves when we were healthy informed the way we thought we would want to be cared for when we were unwell. But how we felt at that time (even though we knew so little about the future illnesses we feared), is taken as the arbiter of how someone should be cared for in their infirmity.

And yet, we know clearly that once someone is ill they see things differently. The healthy do not choose or think the same way as the sick. So often, we see sick people asking for the very care they would have wanted to avoid when they were well. And yet the MCA can require clinicians to avoid treating people in their illness. Many families have said, for example, "she would never have wanted to be treated in this way" when in fact it is clear that now she does want that treatment.

And yet the MCA enables the ideas and prejudices which we had when we were younger and well to become set in legally-binding writing which can then appear to cause substantial harm and distress later.

3. Mental capacity assessments are complex and subject to doubt and uncertainty

The law states that capacity must be assumed until demonstrated otherwise. However that provision protects doctors and nurses who provide poor care more than it protects the sick and vulnerable. For example, a verbally able but mentally inapacitated person may make a very clear rejection of treatment for a short-term consideration, but in fact be failing to understand or believe that not being treated will result in their death. The wording of the MCA effectively protects any clinician who can claim, with minimal justification, that the patient had not been demonstrated to lack capacity. And if the patient is presumed to have capacity and is refusing treatment, then they will be held to have died through their own choices. The doctors are protected because they will claim that they respected the autonomy of the patient.

The construct of "Best interests" which are used to determine treatment, is a construct which itself is based on fallible diagnosis and prognosis. It is widely accepted that doctors are often not able to make statements as to a person's prognosis or diagnosis. And yet, notwithstanding that, the law requires that a 'best interests decision' be made for such people. At times those "best interests" decisions will involve life-saving treatment. And yet they are often built upon uncertain diagnoses and shaky predictions of prognosis. There is a body of evidence for this especially in states of reduced consciousness. We are aware of patients in a locked in state, or seemingly in terminal unconsciousness who make a full recovery. NICE guidance on "End of Life care" sets out clearly that prognosis is far less accurate than many would hope [2].

Worse still, if clinicians do not want to treat a patient, they may well be able to use the provisions of the MCA to avoid treating them by making assumptions about what they would have wanted etc (see the subvertability of best interests decisions below).

4. Best interest judgements are very subvertable

The best interest process, set out by UK law states that decision makers think through the past and present wishes of the patient and also consult with family members etc. While it is deeply shocking that consultation with family members often fails to occur, it must also be recognized that family members do not always incline to decisions which are truly in the interests of the patient. They may, at times, be struggling themselves with their loved one's illness. Or they may even be waiting for an inheritance. Decisions about life and death become made by people who are healthy and have not got experience of being unwell.

Seriously missing from the best interests process is any statement directing decision makers to consider what is good clinical care. In that context, best interests can easily be subverted. A conclusion that it is better for someone not to be treated and to be allowed to die may be entirely inappropriate for an incapacitated person, but very much what the relevant people who (by law) should be consulted really want for themselves.

It is worth noting that as opposed to the "best interests" consideration, Scottish Law uses "benefits" as an overall guide to clinical treatment decisions.

5. The MCA and withdrawal of nutrition and hydration

The MCA can easily be used to deny care and to deny food and fluids etc with the result that death is assured. When the MCA was passed into law, the withdrawal of food and fluids from people in persistent vegetative state had to be agreed by the Court of Protection. That requirement persisted up until the case of Re Y in 2018 when it was decided that if family and clinicians agreed that it is in the best interests of the patient, then clinically assisted nutrition and hydration (CANH) can be withdrawn in the expectation that death will result. And even though death is caused by dehydration and starvation, it is not necessary to put that onto the death certificate.

In addition to that, if it is concluded that it is not in the best interests of the individual to be given food and fluid, the terms and provisions of the MCA make it illegal to give that fluid. Consequently, to withdraw fluid and thus to cause death is not only legal, but giving food and fluid may be illegal. While case law has clearly demonstrated that that is true in CANH it may also be true even of orally administered fluids. As we have said, if it is concluded that giving food and fluids is not in the best interests of the individual, then giving fluids may simply be illegal. And that decision is no longer even safeguarded by the Court of Protection. Therefore, it may be illegal for a family member to offer fluids etc, and we note that, at times, family members who have done this have been threatened by staff saying they would call the police if they persist in offering fluids to their loved one.

While the MCA can enable good care to be imposed upon people who refuse it, it can also become legal tool which makes feeding and hydrating the sick, as well as offering them active treatments, an assault punishable by criminal law. The case of Alfie Evans is a good example of how Best Interests can be used in this way. Although Alfie was a child and not therefore subject to the MCA, Best Interest principles apply just as they do with the MCA. . Lord Macfarlane stated in his High Court Judgment [3] that *"when in relation to all the other factors in* *the case a judge has concluded that it is not in the best interests of that individual to carry on living and it is in the best interests of that individual to be allowed to die, one asks how can it possibly be disproportionate to hold that that person's right to go to a different hospital in a different country to access treatment should in some way alter the outcome that has been determined."* In that case the care that was prevented was transfer to a hospital in Rome for further assessment and care. And Baroness Hale [4] built upon that view when she stated *"It has been conclusively determined that it is not in Alfie's best interests, not only to stay in Alder Hey Hospital being treated as he currently is, but also to travel abroad for the same purpose. It is not lawful, therefore, to continue to detain him, whether in Alder Hey or elsewhere, for that purpose"*. She continue *"The hospital must be free to do what has been determined to be in Alfie's best nterests. That is the law in this country."*

In other words, having concluded that it was in Alfie Evans' best interests to be allowed to die, the State ordered removal of treatment and the State duly denied Alfie the opportunity of treatment elsewhere. Alfie died. The MCA can, in absolutely the same way, make it illegal to offer food and fluid to a dying person.

We should just note here and remind readers that there are circumstances (for example where severe choking will occur and cause great suffering to the individual every time any fluids are offered) when offering food or fluids might be genuinely wrong. Therefore, occasionally, a prohibition on food and fluid may be a reasonable and right clinical decision.

6. The MCA often makes good clinical decision making harder

The purpose of passing the MCA though Parliament was stated (at the time) to be enabling decision making in those who lack capacity. Sadly, the MCA set out a long list of requirements and processes to follow in making decisions. As well as requiring the "least restrictive option" which so often means that the care offered will be less safe etc. (see below), the MCA sets out many processes whereby it may be found that care ought not to be offered. While it also sets out a suggestion that failure to provide care is neglect, the provisions of the MCA mean that clinicians are required to be able to state (and very often to have recorded) that they had thought through the options, and considered all the alternative courses to what they thought was the best and right care.

Perhaps that makes the biggest difference for the simplest decisions. We would all agree that there should be careful thought and consideration given for complex and challenging decisions. But the law states that even for simple decisions (such as the provision of basic care, or cleaning someone up after they have soiled themselves) clinicians and carers must think carefully through the options and consider the alternatives.

In those who lack capacity, the provision of life saving treatment requires consultation with family, a relevant advocate or an independent mental capacity advocate. That may be a significant deterrent to initiating life saving treatment in those who lack capacity. A senior social services manager once reflected upon this stating that *"the MCA is forcing us to take more risks with people who lack capacity"*. While that may sometimes be a good thing, it also shows how much harder the MCA can make enabling good care for those who lack capacity. Many nursing homes now require a 4-5 page capacity assessment to be completed for each person who is to have a flu vaccination. Which undoubtedly shows how the MCA can make simple clinical decisions harder.

The MCA has within it a deeply embedded belief that simply refusing all care is an option even where death may result and even where great suffering may be caused. That is especially true with Advance Decisions to Refuse Treatment but it also affects most other parts of the Act. It is perhaps not surprising that those parts of the Act were especially strongly championed by those who campaign for euthanasia.

That means that even for simple decisions for things such as basic care, if clinicians thought the patient had capacity to refuse and was refusing treatment, then leaving them in their excrement may be defensible. And even if they lack capacity, a conclusion that leaving them was *"less restrictive"* or in their best interests becomes a defensible option.

In the end, leaving people to suffer alone may become a reasonable interpretation of the best way to provide care. It is, after all, the case that the MCA requires that clinicians think like this.

7. The MCA can increase the likelihood the people will suffer neglect

In its draft form, the MCA planned to exclude what was called basic care from the range of care that could be refused. Basic care included washing, dressing, necessary personal care and simple treatments including palliative care and treatment in the last days of life. However, as enacted by Parliament, all care decisions taken for an incapacitated person are subject to the MCA

That means that, for example, for a person with severe dementia who has been incontinent, the MCA sets out a process of capacity assessment, consideration of the options of care and a balancing of those options, as well as a consideration as to whether or not there is a *"least restrictive option"*. What that all means is that care staff are LEGALLY REQUIRED to consider the option of not cleaning and changing a person who has been incontinent. And of course that will also risk increased numbers of pressure sores etc. We are concerned therefore that the MCA may, of its very nature, be increasing the likelihood that people will suffer neglect and poor care. That problem is compounded by issues arising from the *"Least Restrictive"* principle which underpins the working of the Act (see below).

8. The MCA and life-saving treatment

The MCA specifically sets out that life-saving treatment is something that may be initiated, given, withheld, or stopped. And it specifically states that its provisions apply to all those forms of treatment regardless of whether or not the aim of intervention is to preserve life or to end life. That means two things.

Firstly treatment may be withdrawn and if nutrition and hydration is not deemed to be in the best interests of a person then it becomes illegal to offer them nutrition and hydration (see below). Following the case of Re Y in 2018, the withdrawal of nutrition and hydration does not require Court of Protection approval unless there is disagreement. We noted above how hard families find it to disagree with the clinical staff caring for their loved ones. They are very vulnerable.

Perhaps even more remarkably, it will be necessary to involve an Independent Mental Capacity Advocate (IMCA) in cases where nutrition and hydration is to be started and where there is no other relevant person to consult. But if the IMCA or the "relevant person" (relevant persons are most often family members) is not happy (perhaps worrying about their inheritance etc) then it may be necessary to seek the permission of the High Court to give food and fluids. Without the agreement of the High Court, feeding a person may become illegal. It therefore turns out that following the case of Re Y in July 2018, giving food and fluids may well be more stringently "safeguarded" than the withdrawal of nutrition and hydration so that an individual will die.

9. The least restrictive option requires clinicians to provide care which is as close as possible to neglect and negligent care

The MCA states very clearly as one of its five fundamental principles that clinicians must consider the least restrictive option in deciding what care is right. While that sounds very sensible and seemed attractive when the Act was passed, it does produce some very serious dilemmas for families, clinicians and patients.

Consider for example a woman who is old, frail, unwell and who has pneumonia. Ideally intravenous antibiotics are clearly the best clinical option and would be advised without question to younger people or those with capacity. But in a woman who lacks capacity, and even if she is not objecting in any way, the law states that clinicians MUST consider the possibility of oral antibiotics as they are less restrictive but may still work. They are not, in fact, as likely to work. Therefore the woman may be more likely to die. But the law states that the least restrictive option should be considered. And if she might be going to pull out her drip, you can see that the Mental Capacity Act immediately forces clinicians to think about less safe and less effective solutions. Oral antibiotics are less restrictive, and they are an option, and as a result she may well be more vulnerable as a result of the provisions of the MCA than she would have been without it. Not surprisingly, the least restrictive option is almost always a less safe option. If a mentally incapacitated person has a tendency to wander, do you lock the door to prevent them wandering out alone and coming to harm. Or is allowing them the freedom to do that less restrictive of them?

10. Deprivation of Liberty Safeguards

We just note here that the House of Lords found in 2013 that Deprivation of Liberty Safeguards are not fit for purpose. They are cumbersome, process-heavy and do not appear to lead to effective safeguards for patients. And they are expensive to administer. As a result the Law Commission is bringing forwards amendments to the MCA but five years on, those amendments are only just being brought before Parliament.

11. Conclusion

We believe that the MCA has real limitations and poses substantial risks for people who lack capacity. Those risks are even greater in people who lack capacity and who are disabled, elderly, frail or who suffer from dementia etc. The MCA can easily be misused to deny care to such people. While it is accepted that the Deprivation of Liberty Safeguards are not fit for purpose, we are very concerned that other parts of the Act are associated with poor care. Worse, the general provisions of the Act may indeed be causing poor care and poor outcomes. An Act designed to protect the vulnerable may be doing exactly the opposite. It can enable the withdrawal of care, including nutrition and hydration and can be used to cause death by withdrawal of clinically assisted nutrition and hydration. And it asks clinicians to think of alternatives to the best care even in situations such as personal care for incontinence etc.

We believe that the limitations of the Mental Capacity Act, need to be modified by good evidence-based clinical practice which benefits patients and their families. However we also think that the evidence of the MCA doing harm needs to be collated so that is can become coherent. At present, while there are many reports and concerns about it, those reports are either newspaper articles or multiple anecdotes.

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REFERENCES

[1] Code of practice giving guidance for decisions made under the Mental Capacity Act 2005.
Published 22 July 2013 and last updated 12 January 2016 Pub Office of the Public Guardian, London https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice

[2] National Clinical Guideline Centre. Care of dying adults in the last days of life. Clinical guideline NG31
Methods, evidence and recommendations Publishes National Institute for Health and Care Excellence December 2015. Pp61-69. https://www.nice.org.uk/guidance/ng31/evidence/full-guideline-pdf-2240610301

[3] Evans v Alder Hey Children's' NHS Foundation Trust [2018] EWCA 984 (Civ), 25 April 2018, Court of Appeal, per McFarlane LJ, at paragraph 32:

[4] Supreme Court. In the matter of Alfie Evans: permission to appeal application. 20 April 2018.
https://www.supremecourt.uk/news/permission-to-appeal-application-in-the-matter-of-alfie-evans.html