

Mental Capacity Act

This article addresses the failure of the Mental Capacity Act to protect us against legal euthanasia in times where due to illness, accident or disability we lack the capacity to make our own medical decisions.

It wouldn't be unfair to say that Dignity in Dying speak quite fondly of the Mental Capacity Act (MCA). To them it empowers us to plan ahead to a time when we have lost capacity. It allows us to decide to take a more dignified route to death than the one that might be handed to us.

Through Dignity in Dying's sister company, Compassion in Dying, you can download an Advanced Decision Form and make a legally binding decision about the circumstances under which you would prefer to die and, they're quick to add, "there is no need for a solicitor". All this within the power of this piece of legislation known as the MCA. Perfectly legal. Perfectly dignified. But how much of a hand does this 'safeguard legislation' have in the deaths, and future deaths, of those who do *not* wish to die?

The MCA came into force in 2003 as an official piece of legislation that deals with 'empowering and protecting' people who lack capacity. To be without mental capacity means, as defined by the MCA, the inability to make decisions caused by some impairment to the mind or brain. It includes supposed permanent loss of mental capacity such as dementia or a learning difficulty, and temporary losses due to accident, illness, mental illness and even delirium. The full scope it covers is huge. It affects every single adult in the country as each one of us is vulnerable to accident, we will all one day be elderly, and many of us will go on to suffer an illness that directly affects our 'mental capacity'.

However, shortly after it was finalised the bill came under serious scrutiny. While it is one thing to withdraw treatment to terminally ill patients on request, the most worrisome criticisms of the MCA came from the withdrawal of treatment to those who weren't terminally ill, but were disabled, either by accident or birth and indeed the non-disabled such as the elderly.

As more and more stories kept coming in concerns grew. Deaths like that of a woman who went into hospital. Unable to speak to tell people about her pain, she was locked away in the closed ward of a psychiatric unit. In fact, she merely had gall stones. Her gallbladder perforated and she died. To read many more stories like this one, please read the [death by indifference report](#).

The criticisms came down to why these people, and others like them, had no representatives. In fact the MCA scarcely mentioned independent advocates, and in 2007 was amended to do so. Under the new amendment all patients who lack capacity may receive an independent advocate, sometimes called an IMCA, to represent their interest. Two other changes were made, too. The new MCA would include a checklist, to ensure that the [lasting power of attorney act](#) in accordance to the patients best interest. And finally, it was changed to allow for the use of living wills called 'Advance Directives' to represent the patient's wishes. While the public at large has responded positively to this new launch, can we really sleep any easier?

If even health care professionals can stand by while children like [Daisy Healy](#) die of neglect, to rise above this ignorance towards disabled people, we'd all assume that independent

advocates must receive very carefully considered training. What then do we think of the fact that independent advocates are trained for only four days on the implications of this complex piece of legislation that reads hundreds of pages? Or that no particular qualification is necessary to become an advocate and they can come from a number of roughly related careers?

Even just tracking an advocate down can be somewhat of a challenge. When a colleague of mine tried to locate the list of advocates for her area, she was instantly dismissed. I tried writing to them for help for a made-up sick relative and never got any response. What was harder still to understand is what they're even called; calling around nobody seemed to know. They may sometimes be called Disability Liaison Nurses. They may even be called DOLS according to one woman, a nurse, who introduced herself as 'a DOL', but this seems unlikely since DOLS stands for [Deprivation of Liberty Safeguards](#) and refers to a series of rules, not people. The correct name for these advisors is: Independent Mental Capacity Advocate or IMCA's it is they who should and must be made to look after the needs of anyone without 'capacity.'

Though independent advocates are a great idea on paper, it's not clear they're really making that big a difference. The safety of our most vulnerable still seems to fall to the family, that is to their lasting power of attorney.

A second amendment made to the MCA in 2007 was a checklist. The list was designed to make sure that the Lasting Power of Attorney act according to our best interest. It's a horrific thing to imagine a situation where money or convenience could motivate those dearest to us to pull the plug, but it happens. We might all remember the case of [Terri Schiavo](#) who one day collapsed in the early hours of the morning. She was found not breathing and resuscitated later in hospital, but she had suffered brain damage due to the lack of oxygen going to her brain. It could happen to anyone.

Schiavo's family desperately fought for eight years to keep her feeding tube connected as her husband Michael petitioned to have it removed. The courts questioned the integrity of Michael's claim that he knew she would not have wanted to be kept alive, given he would inherit her estate upon her death, and the families' insistence that, as a Roman Catholic, she would not wish to go against the teaching of the church.

After much publicity and even the involvement of the federal government, and the president himself, all Terri's parents cared about was new hope for her recovery, which had started to rise with the possibility of an fMRI and new treatment called VitalStim. But these hopes that were shattered when it was finally ruled that the feeding tube be removed in 2005. She was left to dehydrate and die.

Her parents were all that had kept her alive in those years, and it was their outrage that means we've heard of this case whilst similar cases were not so publicised. We may wonder how many cases there are out there where there is no supportive family at all, instead only, let's call them, 'Michaels'?

Clearly a checklist the family must meet in order to be considered acting in the patient's best interest does come from a very real demand to protect against the likes of Michaels. However it all lies in what those questions are. The checklist asks questions like:

- ‘Did they do whatever’s possible to encourage us to take part in our (the patient’s) decision?’ However, ‘whatever’s possible’ is left to the doctor’s discretion.
- ‘[Did they] do what they can to encourage the persons participation’, and yet treatment isn’t considered a thing that could be done to help them gain more ability to participate. For example, any dehydrated, elderly person could regain their health after appearing to lose capacity on the verge of death merely through being hydrated. That means that, according to this checklist, no family member that *didn’t* insist on hydration for an elderly dehydrated patient, who would therefore by stopping the patient from regaining health and mental capacity, would be in the wrong. The family member would still be considered to be doing ‘what they can to help them participate’.

* Finally, ‘One must not wish to bring about a person’s death’. But this is far too vague a request. The loving supportive family who want to help their relative be relieved of their pain, ‘wish’ to bring about their death. The uncaring family who are looking forward to seeing their Will, also ‘wish’ to bring about their death. What is really being offered here to check the lasting power of attorney’s intentions?

Indeed both the IMCA amendment and the checklist amendment fail us. The only truly effective amendment of the three amendments made was that Advanced Directives, which brings us neatly back to where we started with Compassion in Dying and their eager support in filling them out with no hassle. The MCA now provides that your best interest can be fulfilled through reference to Advance Directives, or living wills. While this may seem like the best chance we have of protecting ourselves, on the flip side we’re now talking about legal euthanasia.

What the MCA glosses over is that once the document is signed with a witness present, the document will be taken as final even at the risk of your life. This is legal euthanasia through the withdrawal of treatment, a horrible death that can take up to 14 days. To read more about death by withdrawal of Artificial Nutrition and Hydration see www.noliverpoolcarepathway.com

Where ever one stands on voluntary euthanasia, living wills should be the hot area that we most need to ensure is handled with the utmost care. If it legalises euthanasia through neglect, then it brings along with it a great deal of responsibility to ensure that it does not lead to a slippery slope, where involuntary euthanasia, where murder, is permissible. What’s worse than the general lack of public concern is that there appears to be need for concern.

Can we really expect that a mentally capable person can truly sit down and make their biggest life decision without extensive support? Are we comforted by the hassle free promise of ‘no solicitor necessary?’ Or that all that is required is a witness. Where are the people that can help guide us through what the decision really means? After all how frequently do we underestimate what we’ll do or want in a difficult, testing situation? How often are we surprised by our own strength, and our own willingness to go through pain and discomfort to survive?

Professor Steven Laureys of University Hospital Liege recently did a study of locked-in syndrome patients to find out if they’re happy. Patients who, for a number of different reasons, are now paralysed with only blinks to communicate were asked if they were, nevertheless, happy, and to everyone’s surprise, three-quarters were. They asked the patients to rate their happiness on a scale of +5 to -5, where +5 meant ‘as happy as the best period’

and then -5 would mean 'as bad as in the worst part of my life'. Only around a quarter were unhappy compared to before. We've got to admit, we just don't know until we know.

If we are legally bound to our own deaths, no matter what we seem to be communicating at that later juncture, all down to essentially ticking off a box years earlier, how is that not a slippery slope?

Dr Richard Lamerton, an expert in palliative care, writes in *The Hour of Our Death*, about his findings that dying patients whose lives are made comfortable in a hospice are 70% more likely to want to enjoy their remaining days, than dying patients in hospitals are. It's an interesting thing I wonder to at least consider: how do our attitudes towards pain and death change how these living wills will be used?

However the most disturbing problem with the MCA is a simple one. It promises to protect our most vulnerable. It promises to protect us in circumstances where, like the victims in the Death by Indifference report, we lose our voice. It is in fact all that protects us. For hundreds of pages it outlines in detail how a doctor or health care specialist that wishes to treat a mentally disabled patient must go about this. However, it has nothing to say about what happens if the health care wishes *not* to treat a mentally incapable patient.

There is no hardcore legislation to tackle this triumphantly complicated legal area. It is a terrifying legal loophole, under which confusion can seemingly justify murder. When Daisy Healy's mother went to the police after her 9-year-old disabled daughter was neglected to death, she was told that no arrests could be made. 'It did not appear to be any one person's fault. It was a general attitude problem.' Where is the accountability? Where is the part of the MCA that outlines whose responsibility it is to make sure this doesn't happen?

All the MCA can pull out in the way of offerings to the voiceless, are Independent Advocates we can't find, a check list for lasting power of attorneys that doesn't appear to check much at all, and the legally binding contract that may in fact bind you to your painful, undesired, and in no way dignified death, because of an ignorant decision you made several years earlier that no longer reflects your true wishes today.

In 2004 government minister Mr David Lammy, the Parliamentary Under Secretary for State for Constitutional Affairs who presented the MCA, spoke at the House of Commons promising that: "we want to ensure... that under the [Mental Capacity Act] it is not possible for someone by omission to act to assist suicide or euthanasia." It's a promise that doesn't appear to be fulfilled.

Should we be asking is this because it's only a matter of time before the only humane apparent solution is to let assisted suicide by deadly injections be legal? The Voluntary Euthanasia Society (VES) certainly seem to think so when they publicly commended the Act for exactly this reason.

The first time I read the Mental Capacity Act, I felt assured that if I, or anyone in my family, ever needed it, it'd protect us. It was long and hard to understand, written for lawyers not for us. But what I grasped of it, it seemed to be on our side. It took months of research to discover the truth about how it's used, and how ineffective it's been. And now I'm frightened. I don't know what to do if I ever need to try to protect a loved one and the only support I'm offered is 'see the mental capacity act'. What can we do to avoid the awful

situation that Daisy Healy's mum had to go through, where she begged them to take proper care of her daughter, and was treated like dirt for it?

The Mental Capacity Act hides an important question in places few of us know to look, it requires that we have a deep understanding of medicine and law—two subjects that, like most highly complex systems, appear almost magical. With this in mind I am reminded now of a very salient point, in the Wizard of Oz Dorothy sings 'we're off to see the wonderful wizard of Oz' the question is what happens if the wizard isn't wonderful?

UPDATE: We are now seeking to introduce an AMENDMENT to the MENTAL CAPACITY ACT 2005. This amendment would be as follows:

“Where a person, when he had capacity, has indicated that he regards it as in his best interests to receive hydration (whether clinically administered or otherwise), whatever the circumstances, that indication shall be regarded as definitive of the question whether it is in the best interest of that person to receive hydration.”