

Submission to the Ad Hoc Joint Committee on the Mental Capacity Bill (NI)

About Compassion in Dying

Compassion in Dying is a national charity that supports people at the end of life to have what they consider to be a good death by providing information and support around their rights and choices. We are the leading provider of free Advance Decisions in the UK and we also conduct and review research into rights and choices in end-of-life care.

Compassion in Dying runs an end-of-life rights Information Line, which covers the whole of the UK. In 2014 we responded to over 2,500 calls, letters and emails and distributed over 10,000 Advance Decision packs, Planning Ahead guides and factsheets via post, our website and at events.

We provide information tailored to the different nations of the UK, including a factsheet on end-of-life rights in Northern Ireland (available here:

<http://compassionindying.org.uk/library/your-rights-in-northern-ireland/>)

The Mental Capacity Bill

Our response to the Call for Evidence focuses on Part 1, the Principles of the Bill, Part 2, Section 11 on Advance Decisions and Part 5, Section 95 on Lasting Powers of Attorney (LPA).

- **Part 1 - Principles of the Bill**

Compassion in Dying welcomes the inclusion of the Bill's five principles and in particular the emphasis that has been placed on supported decision-making in Part 1, Section 5. We also especially welcome the point at Section 7 (6) (a), that *special* regard must be had to P's past and present wishes and feelings (and in particular any relevant written statement made by P when they had capacity) as part of the determination of what is in the patient's best interests. We hope these inclusions will help to address concerns that best interests remains a paternalistic concept that does not sufficiently consider the wishes of the patient. We further welcome the inclusion of the factor that the views of any relevant people must be considered as part of the best interests assessment. This can be very empowering to family members, who are often best placed to provide information about what their loved ones would have wanted.

However, the House of Lords review into the Mental Capacity Act 2005 (MCA) in England and Wales has demonstrated that it is important that healthcare professionals are trained effectively to conduct capacity and best interests assessments and give considered attention to any expressed wishes of the patient to ensure that it does not become a paternalistic exercise. These concerns are pertinent in the operation of each of the five principles. Whilst the principles are good, it is clear that attention must be given to ensuring that they are implemented effectively in practice.

In particular, the presumption of capacity must also be effectively carried out not only when treating a person, but when looking at their past expressed wishes (e.g. if they have an Advance Decision). This should ensure that people with mental health conditions or dementia for example, are not unfairly discriminated against and that they can also feel confident that their wishes will be respected should they lose capacity in the future.

- **Part 2, Chapter 1, Section 11 - Advance Decisions**

Compassion in Dying's strong preference would be for the Mental Capacity Bill to give Advance Decisions statutory force, rather than leaving them to common (court-developed) law.

We acknowledge that the Mental Capacity Bill gives legal force to 'effective Advance Decisions', but it leaves exactly what would classify as an effective Advance Decision to the common law. This has the potential to create confusion both for members of the public who would like to plan ahead for their future treatment in the event of a loss of capacity, and for healthcare professionals who may be faced with an Advance Decision and unsure as to its legal status. Our Information Line receives enquiries from all four countries of the UK. It is undoubtedly much easier for people in England and Wales to understand the legal status of Advance Decisions in these countries (where Advance Decisions have statutory force under the MCA), than it is for people in Scotland, where the Adults with Incapacity Act (2000) supports some of the principles of Advance Decisions without giving them statutory force.

The detail within the MCA which defines valid and applicable Advance Decisions also gives people greater confidence and peace of mind that their Advance Decisions will be respected in the future. This is especially true in the context of Advance Decisions that refuse life-sustaining treatment. The additional criteria not only gives people greater confidence that their wishes will be respected but also makes healthcare professionals more confident in following Advance Decisions in the context of life-sustaining treatment as they can be more certain that the individual definitely wanted to refuse that treatment. We do not feel it would be appropriate or fair to individuals who want to plan ahead for their future treatment, to wait until a suitable case is decided for further clarity.

It is noted from the Second Stage debate that what constitutes an 'effective Advance Decision' will be elaborated upon in the Code of Practice, but a draft Code has not yet been made available for comment. Although this is good, it again has the potential to create confusion amongst the public and professionals. The Bill as a whole respects autonomy and the principles of Advance Decisions, but the provisions do not provide clear guidance as to how people should go about doing so. Leaving the detail to the Code of Practice may mean that individuals and healthcare professionals are less likely to take Advance Decisions seriously, which would in turn seriously limit the uptake and effectiveness of Advance Decisions.

The fact that the Bill would keep Advance Decisions on a common law footing whilst setting out that they can outweigh elements of the statute (Part 2, Chapter 1, Section 11 - the protection from liability does not apply if the person has made an effective Advance Decision; and Part 5, Section 95 - the provision that a person given Lasting Powers of Attorney for health and welfare must act within the confines of any directions in an effective Advance Decision made after or at the same time as the registration of the LPA) also seems likely to create confusion. This is not to suggest that Compassion in Dying disagrees with these clauses; only that their effect would be clearer if Advance Decisions had a more robust definition within the statute. On the present draft of the Bill the rather opaque relationship between Advance Decisions and health and welfare LPAs could have the effect of leading people to only to make LPAs as they have a statutory basis even though writing an Advance Decision may be a more accessible and cost effective way of planning ahead for some people. Alternatively people may do both and risk not having their wishes fulfilled because a court decides that LPAs outweigh Advance Decisions.

A poll commissioned by Compassion in Dying in 2013 found that most adults would want little or no medical intervention at the end of life. More than half of adults (57%) would only want comfort care, 13% would want limited intervention, and just over one in ten (12%) would prefer all available treatment. However, just 4% of the public had made their treatment

wishes clear in an Advance Decision, and 4% had appointed a third party to make healthcare decisions on their behalf if they lose capacity (YouGov 2013). This shows how important it is to increase awareness and access to people's legal rights to make decisions about their medical treatment, so anything that can improve this within the Bill would be beneficial. This of course needs to be accompanied by effective training for healthcare professionals as well as the public, to ensure effective implementation of the Bill and its principles. We would be concerned that the lack of attention given to the details of Advance Decisions within the Bill will actually make it harder to increase awareness and encourage uptake.

Given the commitment to introduce mental capacity legislation in Northern Ireland, it seems to make sense to make the legal status of Advance Decisions as clear as possible so that people have the best chance possible of making use of and benefiting from the new law, and so that healthcare professionals will understand the law and their responsibilities in relation to Advance Decisions.

- **Part 5, Chapter 1, Section 95 - Lasting Powers of Attorney**

Compassion in Dying strongly welcomes the proposal to introduce Lasting Powers of Attorney (LPA) for financial, and health and welfare matters, along the same lines as happened in England and Wales under the MCA. Many people would want the option of nominating a trusted person to make health, treatment and care decisions for them if they were to lose mental capacity or the ability to communicate.

We also welcome the provision in the Bill that a person who is nominating another to make health and welfare decisions for them using an LPA must give explicit instruction to that effect if they want their attorney to have the power to give or refuse consent to life-sustaining treatment.

In terms of administration and implementation of the law in relation to LPAs, it would make sense to work closely with the Office for the Public Guardian (OPG) in England and Wales, which has made significant strides forward in recent years in making the process of filling in the forms for LPAs much more accessible. This can be seen by the recent changes made to the LPA forms (as of 1st July 2015), and the introduction of a digital assistance tool which allows people to complete LPAs online.

There was concern expressed in the Second Stage debate that LPAs are more costly than Enduring Powers of Attorney (EPAs). The Law Society commented that it can cost up to £500 to make an LPA, as well as the £110 required as a registration fee. Compassion in Dying is concerned that these figures are potentially misleading. It is not actually a requirement that a person uses a solicitor to make an LPA, indeed this is a common misconception and the sometimes excessive fees that people hear about (as well as the potentially intimidating nature of having to go through a lawyer) is actually prohibitive to many people, and acts as a barrier to them accessing a key legal tool that enables them to exercise their rights to take control of their treatment and care. The OPG has taken steps to ensure that the process is as accessible as possible, and this has been helped by the introduction of the online digital tool as well as the new forms which are much more appealing to people who wish to fill them out without the support of a solicitor.

Compassion in Dying regularly supports people to complete the LPA forms themselves, and our lottery-funded project *My Life, My Decision*, which runs in partnership with seven local Age UKs provides one-to-one support to people aged over-50 to complete documents such as the LPA. Many service users were not aware that they did not require a solicitor to complete one and having the ability to complete it themselves is not only much better

financially, but reinforces the empowering ethos that is behind the LPA process in the first place.

Compassion in Dying believes it is absolutely vital that there is sufficient awareness-raising amongst the public to demonstrate that they have the option to make an LPA and also that eliminates some of the key misconceptions held. Importantly, the distinction between Enduring Power of Attorney and Lasting Power of Attorney (especially that the former does not cover decisions relating to health and personal welfare) and the fact that a solicitor is not required are both significant issues that must be dealt with to ensure informed awareness and take-up of the LPA process.

Conclusion

Compassion in Dying welcomes the Mental Capacity Bill. We know from enquiries to our Information Line that many people in Northern Ireland want to understand what rights and choices they have in terms of end-of-life care and planning ahead for their future medical treatment. Some have expressed frustration that they don't have the same rights and opportunities in this regard as citizens in the other countries of the UK. If enacted, the Bill would be an important step towards addressing that disparity.

To note: Compassion in Dying was founded by the campaigning and membership organisation Dignity in Dying in 2007. The two are sister organisations, and share a desire to see individual choice at the heart of end-of-life decision making. Compassion in Dying supports the uptake of existing legal rights and is not involved in Dignity in Dying's campaign for assisted dying for terminally ill, mentally competent adults, within the last six months of life.

Compassion in Dying is a separate legal entity from Dignity in Dying, with its own bank accounts, accounting records, and financial governance. It has a separate board of directors/trustees who hold fiduciary responsibility for the charity.

DETAILS OF RESPONDEE

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