TERMINALLY ILL ADULTS (END OF LIFE) BILL
5 STONE BUILDINGS WEBINAR 22 APRIL 2025

Introduction

The provisions of the Terminally Ill Adults (End of Life) Bill 2024 ("the Assisted Dying Bill") touch on areas in which we individually and collectively have expertise, both in the Court of Protection and in our practices dealing with inheritance disputes. We know something of the people whose lives it is likely to affect, both as patients and families and carers considering the choice offered by the Bill, and people in the medical and legal professions. In summary, the core operative effect of the Bill is to partially decriminalise the offence of assisting suicide under s2 of the Suicide Act 1961. The precise shape or form of any state enabled service of assisted suicide is much less clear

We arranged this seminar now as a sort of "emergency podcast" because the Third Reading was originally imminent at the end of April, but it has now been postponed to 16 May 2025. It's also an opportunity to congratulate Ruth Hughes on her very well deserved appointment as KC, excellent in itself and also adds to her weight as someone who filed written evidence with the public bill committee, and whose evidence was commended to the committee by Naz Shah MP.

Our intention is to be informative and not ideological, whatever our individual views of the merits of the legislation as a headline proposition. But it may be helpful to delineate the divide between the enthusiasts and the secular sceptics of it because it explains a lot about attitudes towards specific aspects of the Bill in their progress through Parliament. Essentially the divide is about the exercise of personal autonomy and the nature of barriers to it which are intended to prevent abuse of those who may lack personal autonomy.

Parliamentary progress of the Bill

Following the majority vote at the end of November 2024, the Bill's public committee stage ended shortly before Easter.

The committee accepted relatively few amendments to the Bill and opponents have expressed dissatisfaction about this. The process has prompted some debate about the use of a private member's bill for a measure as consequential as this

Limitations of a Private Member's Bill

A private member's bill does not have explicit government support or state resources devoted to it, either in preparatory work or in its progress. It is introduced to Parliament with far less prior scrutiny or consultation than a government Bill. This Bill was drafted by a retired senior Parliamentary counsel, but effectively in a freelance way on the instructions of the Bill's promoter, Kim Leadbeater MP. It is well known that both ministers of the principal departments whose work would be required to effect the provisions of the legislation oppose it: Shabana Mahmood, minister of justice, and Wes Streeting, minister of health. Junior ministers in their departments: Sarah Sackman and Stephen Kinnock, were members of the Bill committee and voted with its promoter on all amendments.

One of the most acute deficiencies revealed by the process is that there has been no official work on resourcing any state provision either for the NHS to set up an assisted dying service, or for the courts to enable judicial oversight of assisted dying declarations

There's also a sword of Damocles aspect to a private member's Bill. The government could block it or hinder its progress at any time. Inevitably there was speculation about this when the date of the Third Reading was put back.

Private Member's Bills don't get the same amount of Parliamentary time as government Bills. If the Bill runs out of time in this Parliamentary session, it won't be automatically carried over to the next.

Mental Capacity in the Bill

Clause 1(1) A terminally ill person who has the capacity to make a decision to end their own life (and satisfies other eligibility conditions) may be provided with assistance

Clause 3 – capacity to be read in accordance with the Mental Capacity Act 2005

Novelty

Although MCA itself now in force since 2007, this would be new territory for its application, as a threshold to formal validation of a decision taken by an adult with capacity, not as a threshold to a best interests decision taken by a decision-maker on behalf of an adult who lacks capacity. Taking the MCA test of capacity out of the framework of the MCA as a whole invites consideration of its suitability for this task.

It remains outside the zone of collective experience of the Mental Capacity Act, and this brings conceptual challenges in practical application of the test. Information relevant to the decision is essentially existential – weighing up the quality of continuing or extinguishing life.

Existing jurisprudence

2004 – *A Local Authority v Z* [2004] EWHC 2817 (Fam) Hedley J

Court asked to continue injunction under inherent jurisdiction preventing Mr Z from taking Mrs Z to Switzerland for assisted suicide. Refused, accepted evidence

that Mrs Z had capacity to make her own decision, and had done so entirely uninfluenced by anyone else. No detailed discussion as evidence accepted by all parties.

A case which holds up a closer mirror to the world that may come into existence under these laws is *Kings College Hospital NHS Foundation Trust v C* [2015] EWCOP 80 – just under a decade ago, the Court of Protection had to consider whether a woman had capacity to refuse life-saving medical treatment. The court recognised from the outset the value society places on personal autonomy over medical treatment and that it could only make a best interests decision for her if it found she lacked capacity to do so for herself. Context is significant, clinicians seeking a declaration of incapacity in order for court to make a better decision than they thought the woman was making for herself.

C was a woman who had attempted suicide and was almost certain to die without renal dialysis. Although both clinicians and her family tried to persuade the court that she lacked capacity to decide whether or not to consent to dialysis, they were unsuccessful. She had capacity, refused treatment and died shortly after the hearing.

As the judge said, C was a woman to whom the word "conventional" will never be applied. She had led a life characterised by impulsive and self-centred decision making without guilt or regret. She had had four marriages (wife of Bath, five husbands at the church door) and a number of affairs and spent money of husband and lovers recklessly before moving on when things got difficult or the money ran out. She was an entirely reluctant and at times completely indifferent mother to her three caring daughters. C is, as all who know her and C herself appears to agree, a person who seeks to live life entirely and unapologetically on her own terms, that life revolving largely around her looks, men, material possessions and living the

high life. In particular, it is clear that during her life C has placed a significant premium on youth and beauty and on living a life that, in C's words, sparkles…. Living at all costs her sparkly lifestyle

Attempted suicide with paracetamol overdose, doctors hopeful of successful restoration of liver and kidney function with treatment, but prognosis very poor without further renal dialysis, C refused treatment, court asked to assess capacity
Clinicians argued that she lacked capacity because she could not weigh and use the information relevant to making a decision about dialysis, adhering to a rigid belief that there was no hope of recovery, and that was attributable to a personality disorder.

Daughters believed that mother did have capacity to decide whether or not to refuse treatment (and gave evidence of her persistent suicidal intention) – and that she had rationally decided that she did not want to live if she could not regain her sparkle

Court recognised finely balanced case close to borderline of whether or not she had capacity.

J satisfied that C had capacity on functional test but even if she did not, he doubted whether there was a causal relationship with the diagnostic test – recognised that C's decision "will alarm and possibly horrify many", "certainly does not accord with the expectations of many in society" and "indeed, others in society may consider C's decision to be unreasonable, illogical or even immoral within the context of the sanctity accorded to life by society in general"

Case illustrates how difficult it might be to apply the capacity test to a decision similar to that which these Bills would introduce

Proposed amendments relevant to the capacity test in the Bill

Is the MCA test the right test? A number of amendments were rejected by the committee

A number of amendments intended to clarify the application of the Bill to people with existing mental disorders were rejected eg limiting circumstances in which people with anorexia nervosa might become eligible for assisted dying

It has been argued that it is too limited by comparison with assessments done in suicide prevention, and test should be one of "ability" to fully understand assisted dying and its implications. Allan House, a psychiatrist and one of the witnesses to the PBC has written "It has proved impossible to get the Bill's supporters to agree any significant change that would require exploration of and a response to remediable psychological or social influences on the decision to ask for assisted suicide." Amendment rejected

Raising the standard of proof

Proposal to raise standard of proof of capacity to beyond reasonable doubt rejected. MCA has presumption of capacity and Bill does not explicitly reverse this. In practice will positive proof be required and how knowledgeably and stringently will it be assessed?

Evidence given to English Bill committee by group concerned with complex end of life decisions

"The mental capacity to end one's own life is a novel test in assisted dying law and policy. There is reason to believe it is the right test legally and ethically and the public want it. However, it is far from clear that it can be reliably assessed or serve the public policy purposes of the terminally ill adults' bill at this time"

Barbara Rich