

Do No Harm: 'Best interests', patients' wishes and the Mental Capacity Act 2005

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Abstract

The Mental Capacity Act 2005 provides a mechanism for decisions to be made on behalf of individuals who are deemed incapable of making decisions for themselves. Central to the Act is the application of the 'best interests' principle, whereby any decision made must primarily consider what is best for the individual in question. Whilst this principle could be seen as potentially paternalistic in nature, leading to ignorance of individual's wishes, the Act and its code of practice positively encourage the involvement of non-capacitor's in decision making, regardless of the extent of their incapacity. This discussion explores the nature of 'best interests' and the complex legal ramifications of making decisions on behalf of others. It explores the nature of capacity and whether an individual's wishes should always override what is thought to be in their 'best interests'. The discussion concludes that the focus on 'best interests' within the Mental Capacity Act 2005 does not undermine the wishes of individuals who do not have capacity to make decisions on their own behalf. Best interests must, however, be viewed holistically and prospectively, considering all elements (social, emotional and medical) which may have a bearing on the outcome of an individual case.

I. Introduction

An individual's capacity for thought and decision making for all aspects of his life and especially in relation to his medical care is something that many people take for granted. If, however, this capacity is diminished or lost (or may never have truly been present), how and by whom should such decisions regarding one's life be made? The Mental Capacity Act 2005 (MCA)¹ provides a mechanism for decision-making on behalf of individuals over the age of 16

¹ Mental Capacity Act 2005.

who for any reason (whether temporarily or permanently) lack capacity. The Act focuses on the concept of 'best interests'. Section 1(5) states: 'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests'². The application of this principle in a medical setting (as for all settings) requires thought and input from a number of sources, including the individual for whom the decision is to be made. In this essay, I argue that the use of the best interests concept does not undermine the ability of non-capacitor patients' wishes to be respected. Determining a patient's best interests and where their wishes fit into a decision making process is complex, yet the Act encourages open discussion with all parties to ensure best outcomes. It is the determination of capacity and potential changes in capacity over time, along with an individual's change in their own wishes as time progresses, that has more impact on whether their wishes can always be respected.

II. Best Interests Prior to the MCA 2005

The best interests concept is central to the MCA and the decision making for and on behalf of individuals who lack capacity. The application of this concept to the provision of medical treatment for adults who lack capacity (and to more general substitute decision making on their behalf) is derived from the case of *Re F (Mental Patient: Sterilisation)*³, in which permission was sought for the sterilisation of a 35-year-old female who was a resident of a home for the mentally disabled. The individual in question had a mental age of approximately 5 to 6 years but had embarked on a sexual relationship with a male resident at the home. This sparked concerns regarding her potential to become pregnant, a situation that would have been disastrous for her due to her lack of understanding. The request for

² *ibid.*

³ *Re F (Mental patient: Sterilisation)* [1990] 2 AC 1.

sterilisation followed a review of all potential contraceptive measures available and was made by the individual's mother and the authority responsible for the care home. At the time, there was no clear route in common law for determining how treatment of the mentally incapacitated should be decided upon - especially with regard to what was seen as such an extreme form of non-therapeutic treatment.

The House of Lords declared that that the operation could go ahead⁴. The judgment stated that medical treatment could be provided to an adult with mental incapacity (described as 'an inability to consent for one reason or another') if that treatment was shown to be in the patient's best interests⁵. Each of the Lords' judgments quoted the concept of best interests, yet no explanation was provided for what these best interests may be. It is interesting to note, however, considering the statement being discussed within this essay, that Lord Goff commented on how these interests should be judged. He suggested that it was not only the doctors who should make the decision and stated that he anticipated that 'an inter-disciplinary team will in practice participate in the decision' in determining whether treatment was appropriate⁶. This initial declaration, however, did focus on the use of the Bolam test⁷ in determining whether a decision was 'best' based on the absence of negligence in the medical outcome chosen.

A number of further cases have expanded the common law application of the best interests concept in this context prior to it being codified within the MCA. A change in the approach to identifying a person's best interests can be seen, however, with a move away from applying the Bolam

4 *ibid.*

5 *ibid.*, *cf* judgment by Brandon LJ.

6 *Re F* [1990] 2 AC 1.

7 The Bolam test was established in the judgment of McNair J in the case of *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

test in their assessment⁸ to a wider (more holistic) welfare-based review of a person's life requirements (i.e. not simply focusing on the medical perspective) and to a more objective, reasoned basis for decision making⁹.

III. The Nature of Capacity

Capacity can be described as the ability of a person to make a reasoned decision, and under the Act, a person is defined as lacking capacity 'if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain'¹⁰. However, while a person may be deemed as lacking capacity at that particular point in time, this may not always be the case. There are several categories of capacity within which an individual could be placed - from a transient loss of capacity (as may be seen in cases due to episodic illness or drug induced) to cases where capacity has diminished over time (as seen in dementia sufferers whose ability to actively participate in decision making decreases as the illness progresses), to cases where capacity is lost completely and will never be regained (as seen in cases such as Persistent Vegetative State). At this end of the scale, however, there is another important category - those who may never have had capacity due to the presence of a mental disability. Capacity distinctions may be further complicated by the person's actual level of capacity - legally a person is described as being either competent (having capacity) or non-competent (incapacitated),¹¹ but in reality, this is a sliding scale. A person may not be deemed legally competent, but they may still have the capacity for thought and discussion and therefore be able to let their

8 Judgment by P Butler-Sloss in the case of *Re S (Adult patient: Sterilisation)* [2000] 3 WLR 1288, where she dismissed the use of the Bolam test in such cases.

9 The use of a balance sheet approach is described by Thorpe LJ in *Re A (Medical treatment: Male sterilisation)* [2000] 1 FCR 193, CA.

10 MCA s 2(1).

11 MCA 2005.

wishes be known. This should enable them to play a role in making reasoned decisions about issues that would affect their life.

Assessing capacity is the ultimate starting point when making best interest decisions – the Act is careful to point out that a competent person may make a decision that is seen by others as unwise and not in their best interests, but as they are competent, their decision must be accepted¹². An unwise decision does not equal a lack of capacity¹³. When a person is deemed to be incapacitated, a functional test¹⁴ to assess their competence would provide an indication as to their level of capacity and therefore their ability to be involved in decision-making. As will be discussed later, every effort must (and indeed should) be made to involve individuals in the decision process. Functional tests can therefore provide an indication of the level of involvement possible.

Issues in the categorisation of non-capacitors become apparent when providing direct guidance on how best interests are to be determined, and it also demonstrates that different approaches to each category may be required. For those with a transient loss of capacity (at least anticipated to be transient), there may be a reluctance to make certain decisions based on the potential for regaining capacity and the impact on future wishes. As part of the assessment process, the Act requires that a judgment be made on whether the person lacking capacity is likely to regain it at some point in the future¹⁵. Where individuals are losing or have lost capacity, then there may be a greater need to look back at previous thoughts, wishes, and decisions made by that individual when they had full capacity. For those who have

12 MCA s 1(4).

13 See *Re B* [2002] EWHC, in which a tetraplegic woman argued to have her ventilator switched off. She was found to be mentally competent although suffering from a severe disability. Her decision stood.

14 As described in the MCA s 3(1).

15 MCA s 4(3).

never had capacity, they may never have been given the potential to make decisions or to discuss their thoughts and wishes.

How, therefore, can their wishes be determined? Regardless of the category or level of capacity of the person in question, they will all have wishes and feelings that should be taken into consideration when decisions are made. Should the Act therefore distinguish between these categories? What may differ between these groups is the ability to determine what the individual's wishes and feelings may be and the impact of the decision to be made on the future well-being of that person. As the nature of capacity may change in an individual over time, so, potentially, will his or her best interests.

IV. Defining Best Interests

The best interest standard or principle is applied in a number of legal situations when determining the course of action that can provide the best potential outcome for the individual in question. There is no clear definition of best interests in most cases; 'best' is difficult to describe as what is 'best' will differ not only between individuals, but also between different time points in an individual's lifetime¹⁶. Someone taking 'control' of a person's life through the making of decisions on their behalf can be viewed as paternalistic in nature. As Coggon states¹⁷, it should, however, not be viewed simply as a concept; rather, it should instead be seen as 'a construct for good decision-making'. He additionally states that it is a 'goal to aim towards in all cases', acknowledging that a singular best interest may not be possible to determine in each case.

16 John Coggon, 'Best Interests, Public Interest and the Power of the Medical Profession' (2008) 16 *Health Care Analysis* 219; *cf* Loretta M Kopelman, 'The Best Interests Standard for Incompetent or Incapacitated Persons of All Ages' (2007) *Journal of Law, Medicine, and Ethics* 187.

17 Coggon (n 16) 219.

For a competent individual who is able to make their own decisions, a best interest choice is subjective, as it is based on their own thoughts and feelings at that time. When one is trying to determine the best interests of another, it should become an objective decision process based on a number of identified factors (the approach fostered by the MCA). If the individual is involved in the discussion, however, one confounding element in this process is that subjective elements (their thoughts, wishes, and feelings) must be included within the objective analysis. Does this potentially change the objective nature of the discussion? Can a truly objective discussion take place around issues that would normally be seen as subjective?

The Act itself does not try and define what someone's best interests might be. This could be seen as a weakness of the Act, considering the potential gravity of the decisions that may need to be made on another person's behalf. Would a more precise definition provide better guidance for how best outcomes are achieved from the application of the Act? The nature of the actual outcome is difficult to determine, as the Act can be applied across a range of decisions/acts that need to be carried out on behalf of an individual lacking capacity. This approach should instead be viewed as a strength as it allows a more flexible approach to decision making to be applied on an individual case basis.

The code of practice (CoP), written to provide guidance to users of the Act¹⁸, clearly demonstrates this flexibility. The CoP provides a set of guiding principles for how an individual's best interests can be ascertained, including the identification of their views (past, present, and future); consulting others who may be able to provide a view on that individual; the restriction of rights (avoiding conflict with the European Convention on Human Rights); and, most importantly, encouraging participation of the individual

¹⁸ Mental Capacity Act Code of Practice 2007.

involved. What the Act encourages is a full and frank discussion of all the contributory factors (both good and bad) surrounding the decision to be made.

Trying to determine an individual's best interests is therefore a potentially complex process. It may not be readily apparent what the best interests of an individual may be, and a careful weighing up of all factors that could influence the potential outcome needs to take place. The preferred method for this process is the use of a 'balance sheet' approach, as first described by Thorpe LJ in his judgment on the case of *Re A (Mental patient: Sterilisation)*¹⁹. He proposed the use of a balance sheet (as applied in financial matters) to determine what a person's best interests might be. He described the drawing up of two columns, one containing a 'factor or factors of actual benefit' and then 'counterbalancing the dis-benefits to the applicant'²⁰. If one column is in credit compared to the other, then that is where the balance of best interests is said to lie. This approach allows for an objective overview of the issues at hand.

The issues that need to be reviewed for each individual case will vary, but as illustrated in earlier common law examples prior to the MCA, they should encompass all aspects of the decision that will affect the individual. These are not confined to clinical issues alone, but should also include consideration of the social, emotional, and welfare issues that may affect the individual. As Thorpe LJ stated in *Re A*, the 'evaluation of best interests is akin to a welfare appraisal'²¹. Welfare appraisals, such as that used within the Children Act 1989, require a thorough review of all factors that impact the individual who is at the centre of the discussion, and the same approach should be applied in

¹⁹ *Re A* [2000] 1 FLR at 555.

²⁰ *ibid.*

²¹ in *Re A* [2000] 1 FLR.

cases under the MCA. As McGuinness stated²² in her discussion of best interests as a pragmatic approach, a 'best interests' standard should be seen as 'not telling us which interests to protect,' but that it can 'act as a general principle stating that we should reach the best decision overall'.

V. Participation of the Incapacitated Individual

Mental incapacity may stop people from making a reasoned independent decision regarding a course of action that involves them. It does not preclude them, however, from being involved in the decision making process. The Act encourages active participation by the incapacitated person in the decision making process to ensure that their wishes are taken into account²³. In terms of respecting the wishes of non-capacitor individuals, this can be seen as a strong point for the Act. By discussing the decisions that need to be made, including a review of all possible options and outcomes, then the wishes, thoughts, and feelings of the individual can be ascertained and should then be taken into account when the final decision is made.

There are potential problems, however, that need to be overcome, especially when considering varying levels of capacity. The major issue is that of communication, such as whether the person in question has the ability to communicate their thoughts and wishes. This could be due to a complete inability to communicate or a lack of clarity in their communication, whether verbal or nonverbal. There are clear cases where communication is impossible (e.g. patients in a persistent vegetative state); however, for many others, the forms of communication may be many and varied. Patients who have lost capacity may have diminished abilities in verbal communication or may require the use of nonverbal methods for communication, such as the use of

22 Sheelagh McGuinness, 'Best Interests and Pragmatism' (2008) 16 Health Care Analysis 208.

23 MCA s 4(4).

signboards or other methods that require translation by a carer. In cases where a person has never had capacity, their language abilities may be restricted and may require some form of interpretation, although the use of an interpreter or translator in such a process does potentially introduce an element of bias that is different from the true wishes of the patient. For example, carers may try to provide their version of the individual's thoughts, believing that to be of more benefit to the patient.

As discussed earlier, patients who have never had capacity may never have had the opportunity to make decisions on their own behalf, so it may be difficult for those individuals to articulate their wishes. Where an individual's lack of capacity is due to a mental disability, then they will likely not fully understand the issues facing them, and all that may be ascertained is their likes and dislikes around certain issues. These should not be ignored, however, as they may still have important bearing on the final decision-making.

Patients who have lost capacity at the point of decision-making, (and are unable to actively contribute to the process) do have another route by which their wishes can be taken into account - through the use of advance directives. The Act states that when these advance directives involve end-of-life treatment decisions, they must be adhered to²⁴ if they were written at a point in time when the person did have capacity. As part of the participative approach, other written orders should be reviewed; however, the nature of the orders and the level of capacity of the individual at that point must be taken into account.

VI. The Decision Making Process - Who Decides?

In trying to determine all the factors that may be involved when defining an individual's best interests, a variety of people need to be involved in the decision making process

²⁴ MCA section 24.

- this refers back to Lord Goff's comments in *Re F*²⁵ regarding the use of an 'inter-disciplinary team'. No person exists on his own - we all interact with a number of people, including family members, friends, carers, and medical personnel, during our lives. Each of these individuals may have an insight into what the incapacitated person's thoughts and wishes may be and should therefore be involved in the decision making process. The British Psychological Society suggests that a 'best interest group meeting' should be held and chaired by one individual in order to determine the best outcome for the person involved²⁶. Some incapacitated individuals may have previously elected someone to be their voice in these matters, up to the level of Lasting Power of Attorney, but this will not be the case in all situations.

As discussed previously, the Act does appear to encourage discussion as an important part of any decision making process for determining best interests. By involving a group of people in the process, a fuller discussion of all the issues that play a role in this process can take place. The aim should be to gain group consensus in decisions, but with a variety of people, all with different emotional and other attachments to the individual in question, there are likely to be disagreements.

What must be remembered through all discussions is that the best interests of the individual in question should take primary place. When discussing the welfare - especially the social welfare - of an individual, it is difficult to discuss this in isolation from the persons who interact with the incapacitated individual on a regular basis, especially family members, carers, etc. Choudhry²⁷ compares the approach

25 *Re F* [1990] 2 AC 1.

26 British Psychological Society, 'Best Interests: Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves' (2007) Accessible at: <http://www.mentalhealthcare.org.uk/media/downloads/Best_Interests_Guidance.pdf> Last accessed 29 April 2013.

27 Shazia Choudhry, 'Best Interests in the MCA 2005 - What Can Healthcare Law Learn From Family Law?' (2008) 16 Health Care Analysis 240.

under the MCA with that used under the Children Act 1989. While the Children Act openly mentions the impact of decisions on others involved, the MCA, as presented, is completely focused on the individual's interests. By focusing on the individual, their interests are given the primary place at all times - but should the interests of others be taken into account? This may move the discussion away from a patient's wishes, but due to their incapacity, they may not understand the implications of the decision they are involved in, which could ultimately lead to honouring their best interests at that point that ultimately has an adverse effect on their future wellbeing.

It is not appropriate for the Act to define exactly who should be involved in the decision making process, and the membership of the decision group should be formulated specifically for each individual case. There have been a number of discussions as to who should ultimately make a decision but to reach such an objective decision, a dispassionate view on the matter is required. Family members with strong emotional attachments may not be able to take this dispassionate view, while doctors may be too focused on clinical requirements. A multi-disciplinary team led by a neutral individual (potentially with some understanding of incapacity) may well provide the best outcome for the individual in question.

VII. Alternative Approaches

Before making a final comment on whether the approach in the MCA undermines the best interests of an individual, there is a need to look at potential alternative approaches that could be applied. The closest alternative is that of substituted judgment²⁸ (as used in the United States), where an individual must try to place themselves in the position of the incapacitated patient when determining the decision that must be made. This is a much more restrictive

28 Kopelman (n 16) 187.

approach, however, in terms of determining the individual's thoughts and feelings and has higher potential for undermining their best interests.

It is not easy to define other alternative approaches aside from requiring that all individuals who have capacity to make advance directives or to at least letting their feelings and wishes be known at an early age. These would later need revising, as it is known that thoughts and feelings change over time, and when placed in the situation of losing capacity, how can one determine his or her own thoughts? We are, however, still left with the issue of those who have never had capacity.

VIII. The Careful Balancing Act - Undermining or Empowering?

The balancing act that is required for determining best interests is, as has been discussed, not a simple one, nor should it be expected to be. When an individual has the ability to take part in this process, every effort should be made to determine what their wishes might be. These must not be ignored against the backdrop of clinical or other issues that are included in the decision making process—the individual's wishes should be given a voice, though not an overpowering one. They should not be allowed to override the other viewpoints, just as another person's viewpoint should not override that of the incapacitated person. At the same time, the process should not simply pay 'lip service' to the involvement of the incapacitated individual. Rather, the decision making team should fully consider their thoughts.

The Court of Protection²⁹ has an important role to play in this process. This court is only invoked when a decision cannot be made due to disagreements among the decision making team. When they are asked to make a decision, they must demonstrate that they have included the

²⁹ MCA 2005.

wishes of the individual in their reasoning and demonstrate the balanced approach that is required in action.

IX. Conclusion

Common law has led to the development of the best interests concept in relation to individuals who lack the capacity to make their own decisions. This has expanded over time to require a review of not just medical/clinical aspects of a person's health, but also their welfare, social, and emotional requirements. For a thorough review of these various factors, involvement from a number of parties with links to the individual in question is required to determine what that person's thoughts, views, and wishes might be. This is a complex process that is further complicated by the past, present, and future capacity of the individual in question. What must be remembered is that their welfare and their wishes must be considered first in all discussions, ensuring that they are respected when possible. This does not mean that their wishes must be adhered to, but that sound reasoning and balancing must be applied by the person designated to make the decision on their behalf to ensure that their viewpoint is respected at all times. The focus of the Act should remain on the discussion of best interests, not on defining what the outcome should be; therefore, decisions made by the Court of Protection must take care not to set a dangerous precedent in seeming to ignore a patient's wishes. As our understanding of capacity and the nature of decision making in those lacking it evolves, so too should their involvement in the process, although this does not negate the best interests approach for determining the decisions that must be made.

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