

# A Review of Advance Directives

## What circumstances justify interference with the wishes expressed in an advance directive?

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**Abstract-** The use of an advance directive, when drafted in accordance with the MCA, allows a person the right to refuse specified treatment at a later stage of their life, should they become incapacitated. This means that they, rather than others, can determine what would be in their own best interest. However, even when a person has made an advance directive, their express wishes can be overruled by the court if they have acted in such a way, or there has been a change in circumstances, that is inconsistent with their advance directive. That is, in the event of clear inconsistencies with an advance directive, the court will rule in favour of the preservation of life. Thus, in certain circumstances, it may be justifiable for an advance directive not to be binding.

This review aims to evaluate the practices around advance healthcare directives in England and Wales. In particular, it focuses on advance directives for refusal of life-sustaining treatment, and how the courts interpret Section 25(2) (c) MCA in determining when an advance directive is no longer valid or applicable to the specified treatment as a result of inconsistencies subsequent to the document's drafting. Furthermore, it contends that a mandatory capacity assessment prior to drafting an advance directive could eliminate contentious issues at a later stage.

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**Index Terms**—Advance Directives, Autonomy, Capacity Assessment, Ethics, Medical Treatment.

### I. INTRODUCTION

Advance directives align with the principle of autonomy; however, in English law, these can be interfered with by the courts. For example, this will be the case 'If the person has done anything else clearly inconsistent with the advance decision remaining his fixed decision.'<sup>1</sup> This means that, where a person has clearly cast doubt on their advance directive, the courts may be obliged to invoke Section 25(2) (c) Mental Capacity Act 2005 (the "MCA") and declare it invalid. However, it is contended that, should the courts exercise this option, then respect for autonomy becomes redundant. Thus, rather than applying Section 25(2) (c) MCA, it can be argued that, in keeping with the right to autonomy, the courts should respect advance directives to be conclusive in all circumstances, even if, at a later stage, a person has cast doubt on the validity of the wishes expressed therein. Nonetheless, the MCA Code of Practice makes clear that the courts do have the jurisdiction to decide on advance directives '...where there is genuine doubt or disagreement about an advance decision's existence, validity or applicability. But the court does not have the power to overturn a valid and applicable advance decision'.<sup>2</sup>

Although advance directives are governed by a legal framework under the MCA, this paper seeks to address the gap in the current law; in particular,

<sup>1</sup> Section 25(2) (c) Mental Capacity Act 2005 (MCA 2005).

<sup>2</sup> Mental Capacity Act Code of Practice pg.177 Para [9.67]<<http://Mental-capacity-act-code-of-practice.pdf> (publishing.service.gov.uk)> accessed 25 February 2024.

where there is no requirement for a person's capacity to be determined prior to drafting an advance directive.

This review seeks to evaluate practices around advance directives in England and Wales. First, it will argue that a person's advance directive should be respected, in keeping with the principle of autonomy. Second, it will contend that an advance directive to refuse treatment should not be binding under all circumstances if the person has cast doubt on the validity of their advance directive by acting in such a way as to be inconsistent with what they had initially expressed therein. It will focus on Section 25(2) (c) MCA, and how the courts interpret inconsistencies with respect to advance directives. Third, it will consider the effect of advance directives in cases where a patient's circumstances have changed since drafting their advance directive, and the challenges faced by clinicians when interpreting advance directives. Fourth, it will examine whether England and Wales should mandate a capacity assessment, in accordance with the MCA, prior to a person making an advance directive. Finally, it will ask whether the courts should respect advance directives in circumstances where there appear to be inconsistencies with the wishes expressed therein, per Section 25(2) (c) MCA.

## II. ADVANCE DIRECTIVES IN ENGLAND AND WALES

An advance directive is a legally binding document provided that it complies with the requirements set out in the MCA. In essence, it enables a person to set out their express wishes regarding future treatment in the event that, at a later stage, they become incapacitated to make the decision to refuse the specified medical treatment. As Section 24 of the MCA states:

“Advance decision” means a decision made by a person (“P”), after he has reached 18 and when he has capacity to do so, that if—  
(a) at a later time and in such circumstances

as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and (b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.<sup>3</sup>

It is not mandatory that an advance directive be in writing, except in circumstances where a person decides to refuse life-sustaining treatment. If it complies with the requirements set out in the MCA,<sup>4</sup> and is thus valid and applicable to the specified treatment,<sup>5</sup> then in essence an advance directive must be complied with. With respect to life-sustaining treatment, this means that, where an advance directive complies with formalities under Sections 25(5) and 25(6) MCA, it is also legally binding and a clinician is bound to follow it. ‘Healthcare staff must respect this decision if it is valid and applies to the proposed treatment.’<sup>6</sup> An advance directive must thus comply with Section 25 MCA and be ‘valid and applicable to the treatment’.<sup>7</sup> Where a patient is treated contrary to their advance directive, a clinician can be held liable for battery against the person. As succinctly put by Poole J, ‘An adult who has capacity to make a decision about receiving blood transfusion and who found themselves in Mrs W’s position, could refuse blood transfusion and their decision would have to be respected, even if the decision were likely to have fatal consequences’.<sup>8</sup> It is not a matter for clinicians to override the wishes of the person, even if the person has made a decision that will have grave consequences.

The term “valid” ensures that an advance directive complies with the formalities and legal requirements as set out in the MCA. This highlights the importance of adhering to the legal procedures for an advance directive, in order to prevent ambiguity. The term “applicable” implies that the advance directive is relevant to the specified proposed treatment. The effect of an advance directive means that, if it is ‘valid and applicable’<sup>9</sup>

<sup>3</sup> Section 24 MCA 2005.

<sup>4</sup> See Sections 24-25 MCA 2005

<sup>5</sup> Section 25 (1) (a) (b) MCA 2005

<sup>6</sup> [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/921428/Mental-capacity-act-code-](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-)

[of-practice.pdf](#)> accessed 3 January 2023, MCA Code of Practice 2005, para. 6.37, p.105.

<sup>7</sup> Section 25(1) (a) (b) MCA 2005.

<sup>8</sup> *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52 Poole J [2].

<sup>9</sup> Section 25(1) (a), (b) MCA 2005.

then a person has the right to have their wishes respected irrespective of personal views. However, this is not always absolute; if there is ambiguity in the advance directive which makes it no longer valid and applicable to the specified treatment, a person can be administered treatment contrary to their written wishes. Thus, as Munby J states, ‘The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.’<sup>10</sup>

### III. CAPACITY ASSESSMENT AND THE CONFLICT WITH ADVANCE DIRECTIVES

The issue with advance directives is that there is no requirement under the MCA that, prior to making an advance directive, the person must undergo a capacity assessment. Thus, if a person has an advance directive, it can be questioned whether they had capacity at the time of drafting the document. To overcome this issue, there should be a mandatory requirement for a formal capacity assessment before an advance directive is drafted, rather than relying on the assumption that the person was capacitous. As Section 1(2) MCA states, ‘A person must be assumed to have capacity unless it is established that he lacks capacity’,<sup>11</sup> and this applies to a person who has drafted an advance directive. The Mental Capacity Code of Practice also affirms this position when it states that ‘...healthcare professionals should always start from the assumption that the person had the capacity to make the advance decision.’<sup>12</sup> The notion of presuming the person’s capacity at the time of drafting increases the chances that, at a later stage, there will be difficulties proving said capacity when an advance directive becomes contentious.

Heywood points out:

First, a formal assessment of capacity at the time of the creation of an advance decision would not be absolute conclusive evidence of capacity. That is to say it would not mean

that a formal assessment and finding of capacity at the time an advance decision was made could never be disproved from that point onwards.<sup>13</sup>

Nonetheless, in my view, assessment of capacity before drafting an advance directive could ensure more certainty and whether the individual meets the requirements of capacity testing as set out in the MCA. According to Auckland, ‘As a doctor later called upon to implement a directive has no opportunity to assess whether the person would have had capacity, it would not therefore seem such a significant step to require clear evidence of a contemporaneous capacity assessment at the time of drafting the decision.’<sup>14</sup> Thus, it is important that there be a mandatory requirement to undergo a capacity assessment before drafting an advance directive. This would avoid future ambiguity and contentious discussion between clinicians and the parties involved when a person is no longer able to make decisions regarding their treatment.

### IV. CIRCUMSTANCES UNDER WHICH ADVANCE DIRECTIVES CAN BE INVALIDATED OR SHOULD NOT BE UPHeld

Whilst advance directives should be ethically respected, there are circumstances where they should not be binding. Auckland makes the valid point that, where a person has made an advance directive, it is important to ensure that their decision at the outset of drafting the directive was autonomous to begin with.<sup>15</sup> She points out the need to have in place safeguards before a person drafts their advance directive. As she succinctly puts it ‘there are so few legal safeguards in place to ensure that advance decisions are autonomous at the time of drafting. In the absence of these, we cannot be justified in upholding an advance directive.’<sup>16</sup>

Auckland recognises that ‘the law must take steps to better safeguard the authenticity and relevancy of

<sup>10</sup> *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), [2003] 5 WLUK 168 Munby J [24].

<sup>11</sup> Section 1(2) MCA 2005.

<sup>12</sup> <[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/921428/Mental-capacity-act-code-of-practice.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf)> accessed 3 January 2023, para 9.39, p. 169.

<sup>13</sup> Rob Heywood, ‘Revisiting Advance Decision Making Under the Mental Capacity Act 2005: A Tale of Mixed Messages,’ (2014) *Medical Law Review*, 23, pp. 81, 93.

<sup>14</sup> Cressida Auckland, ‘Protecting me from my Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia,’ (2018) 26 *Medical Law Review*, 73, 84.

<sup>15</sup> *Ibid.*, 75.

<sup>16</sup> *Ibid.*

directives, to ensure that only those that are truly autonomous are upheld'.<sup>17</sup> However, this could prove difficult given that there is no way to determine whether the person was under any influences that may have made their decision non-autonomous.

In *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52, the Court of Protection considered whether there was a binding advance directive. In this case, an 80-year-old Jehovah's Witness suffered from severe anaemia caused by internal bleeding as a result of an ulcerated gastric tumor.<sup>18</sup> 'In 2001 she had drafted an advance decision to refuse any blood transfusion in the event that she had lost capacity.'<sup>19</sup> The court held that the patient lacked the capacity to 'refuse blood transfusion',<sup>20</sup> and more so, the advance directive which she made in 2001 was invalid because of her inconsistent acts. As Poole J pointed out, 'The Trust relies on this as being clearly inconsistent with the advance decision remaining Mrs W's fixed decision.'<sup>21</sup> There were several acts committed by the patient which clearly demonstrated inconsistency with her advance directive. For example, in one instance the patient had agreed to have a blood transfusion, and then, 'thirty minutes'<sup>22</sup> thereafter, stated that she had not consented to the blood transfusion.<sup>23</sup> On another occasion, she would agree to a blood transfusion if, in her own words, 'it was clean blood'; 'blood free from diseases'.<sup>24</sup> These occasions demonstrated actions contrary to her advance directive, in which she had made it clear that she would not accept any form of blood or blood products.<sup>25</sup> Thus, an advance directive can be overturned by the courts where a change of circumstances or inconsistencies makes it no longer 'valid and applicable to the treatment'.<sup>26</sup> This case demonstrates the importance of ensuring that an act undertaken at a later stage does not go contrary to your express wishes as set out in your advance directive. It is clear in this case that, even

though her wishes were to refuse any blood or blood products in the event that her life was at stake, the patient had clearly acted inconsistently with her fixed decision as per her directive.

Similarly, in *HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)*, [2003] 5 WLUK 168, the decision to administer a blood transfusion to a converted Muslim was disputed among the parties involved in the proceedings. In this case, the patient had been raised as a Jehovah's Witness until such time as she renounced her faith. The patient's father contended that his daughter was now in a relationship with a Muslim man, and that she had

clearly shown a commitment to the Islamic faith by revoking all of her previous activities as an observant Jehovah's Witness.<sup>27</sup> It was argued that in the current circumstances she would have consented to the proposed blood transfusion. On the other hand, her mother, an observant Jehovah's Witness, refused to consent to the proposed treatment, as she asserted that her daughter would object to such treatment based on the advance directive that was still in force, and that the advance directive should be followed in any event. The courts agreed with the clinicians that the patient had acted inconsistently with her advance directive when she converted to another religion.<sup>28</sup> Thus, an advance directive that leaves ambiguity will become ineffective; as Munby J puts it, 'AE's rejection and abandonment of her faith as a Jehovah's Witness deprives the Advance Directive of any continuing validity and effect.'<sup>29</sup> The case demonstrates the potential effect of a person's beliefs on the validity of an advance directive, especially when there is a dispute over whether such beliefs are inconsistent with the wishes expressed in the advance directive; in this case, the refusal of any blood transfusion.

In this case, had the court ruled that the advance directive was binding, the person's life could have been at stake on the grounds of a belief that was no

<sup>17</sup> Ibid, 76.

<sup>18</sup> *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52 [1].

<sup>19</sup> Ibid, [3].

<sup>20</sup> Ibid, [9].

<sup>21</sup> Ibid [6] Poole J

<sup>22</sup> *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52 [6].

<sup>23</sup> Ibid.

<sup>24</sup> *Re PW (Jehovah's Witness: Validity of Advance Decision)* [2021] EWCOP 52 [16].

<sup>25</sup> Ibid [3].

<sup>26</sup> Section 25(1) (a) (b) MCA 2005.

<sup>27</sup> *HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)*, [2003] 5 WLUK 168 [13].

<sup>28</sup> Ibid [40].

<sup>29</sup> Ibid, [49] Munby J.

longer held. That is to say, if an advance directive was drafted that refused all blood products at the outset but was no longer applicable due to the person's current beliefs, there is no reason why the advance directive should still be binding. Thus, the court's decision to invalidate the advance directive in this case was, in my view, ethically correct. It is quite feasible that the person may have wanted life-saving treatment after converting to another religion but had not updated their advance directive to that effect. The courts can only go by the evident inconsistencies, if a person's life is at stake, irrespective of the express wording of the advance directive. This case also highlights the importance of regularly updating an advance directive.

#### V. LEGAL STANDARD AND EVIDENTIARY PROOF IN ADVANCE DIRECTIVES

The legal and evidentiary burden of disproving the validity and applicability of an advance directive is not covered within the MCA. Case law has alluded to this being placed on the person challenging the validity of the advance directive.<sup>30</sup> Kessel makes the observation that 'In the future one can envisage the courts calling on doctors' evidential opinions of competence when determining the validity of an advance directive.'<sup>31</sup>

In discussing the burden of proof in the case of *HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)*, [2003] 5 WLUK 168, Munby J said that 'An adult is presumed to have capacity, so the burden of proof is on those who seek to rebut the presumption and who assert a lack of capacity. It is therefore for those who assert that an adult was not competent at the time he made his advance directive to prove that fact.'<sup>32</sup> It is clear in this case that the burden of proof fell on the clinicians to disprove the validity and applicability of the advance directive, as they were the ones asserting its invalidity with regard to the proposed treatment.

In the mother's case, the burden of proving the continued validity and applicability of the advance

directive rested on her, as she maintained that the advance directive was binding and that her daughter could not receive any blood or blood products, because to do so would be contrary to her wishes expressed therein. As Munby J succinctly puts it: 'In my judgment, although the burden of proof on the issue of capacity is on those who seek to dispute it, the burden of proof is otherwise on those who seek to establish the existence and continuing validity and applicability of an advance directive. So, if there is doubt that doubt falls to be resolved in favour of the preservation of life.'<sup>33</sup>

Thus, a person who seeks to rebut the validity and applicability of an advance directive must produce compelling evidence to prove that it is invalid and thus should not be relied upon. As Munby J puts it, 'But the more extreme the gravity of the matter in issue so, as it seems to me, the stronger and more cogent must the evidence be.'<sup>34</sup> 'The question of whether an advance directive admittedly made at some time in the past is still valid and applicable may require especially close, rigorous and anxious scrutiny.'<sup>35</sup>

#### VI. ETHICAL REASONING FOR RESPECTING ADVANCE DIRECTIVES

In the words of Munby J, 'An advance directive is, after all, nothing more or less than the embodiment of the patient's autonomy and right of self-determination.'<sup>36</sup> The notion of respecting a person's advance directive lies in the principle of autonomy. A patient should have the autonomy to make decisions about life-saving treatments, even if their decision appears irrational given that denying medical treatment could put their life at risk. Advance directives allow a person sovereignty in determining what is right for them, even if their view seems wrong to others. As Schicktanz puts it, 'The need seems more likely be triggered by the individual wish to care about the own death and to clarify one's very personal ideas concerning the own body—in order of being reflective of one's own identity.'<sup>37</sup> A person may desire the autonomy to

<sup>30</sup> See *HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)*, [2003] 5 WLUK 168.

<sup>31</sup> Anthony S Kessel 'Advance directives in the UK: legal, ethical, and practical considerations for doctors', (1998) *British Journal of General Practice* 48 1263, 1264.

<sup>32</sup> *HE v A Hospital NHS Trust [2003] EWHC 1017 (Fam)*, [2003] 5 WLUK 168 [20] iii Munby J.

<sup>33</sup> *Ibid* [23] Munby J.

<sup>34</sup> *Ibid* Munby J.

<sup>35</sup> *Ibid* [25] Munby J.

<sup>36</sup> *Ibid* [37] Munby J.

<sup>37</sup> Silke Schicktanz, 'Interpreting Advance Directives: Ethical Considerations of the Interplay Between Personal and Cultural Identity,' (2009) 17 *Health Care Anal.*, pp. 158, 160.

control their life and not be subjected to what others believe to be in their best interest. Thus, the courts' intervention in advance directives raises ethical considerations as to whether this invades a person's right to autonomy. After all, the person made the advance directive knowing that it would one day come into effect. They could not foresee that if they converted to another religion, for example, this would render their advance directive invalid. Thus, it can be questioned whether the express wishes contained in the advance directive should remain binding, even in the event of slight inconsistencies.

The right to autonomy is not always absolute, even if a person has clearly expressed in an advance directive that they will not accept any form of medical intervention if their life was at stake. The case of *A Local Authority v E & Others* [2012] EWHC 1639 (COP), [2012] 6 WLUK 325 (*E*) clearly considered the validity and applicability of a person's advance directive in the context of anorexia nervosa. The courts had to consider whether the patient had the capacity to make decisions regarding her medical treatment by forcible feeding; if she was found to lack capacity, the courts would determine the treatment that would be in her best interest. This case highlights the issue that arises when an advance directive clashes with medical opinions. Here, the patient, *E*, was a 32-year-old woman suffering 'with anorexia nervosa and other related health conditions'.<sup>38</sup> The Local Authority had made an urgent application to the court as the patient's 'death was imminent'<sup>39</sup>; moreover, they contended that 'E's position should be more fully investigated'.<sup>40</sup> With regard to *E*'s advance directives, the courts refused to accept that either the advance directive made in July 2011 or that made in October 2011 was valid.<sup>41</sup> In respect of the October 2011 advance directive, the patient had clearly acted in ways which were inconsistent with it 'remaining her fixed decision'.<sup>42</sup> Several of *E*'s acts demonstrated this; for example, the Court of Protection cited that on one occasion, 'During a psychotherapy session on 12 November 2011, she said that she had made up her mind to

live'.<sup>43</sup> This represented a clear contradiction of the advance directive that she herself had drafted. By expressing her wish to live after stating in her advance directive that she would refuse 'tube feeding or life support'<sup>44</sup>, *E* had acted in a way that the court would deem inconsistent per Section 25(2)(c). However, because the courts had concluded that she had not had capacity at the time of making the advance directive, it was immaterial for them to determine whether she had subsequently acted inconsistently.<sup>45</sup> Interestingly, the issue of capacity assessment with respect to advance directives was emphasised, as Jackson J clearly stated:

I find on the balance of probabilities that *E* did not have capacity at the time she signed the advance decision in October 2011. Against such an alerting background, a full, reasoned and contemporaneous assessment evidencing mental capacity to make such a momentous decision would in my view be necessary. No such assessment occurred in *E*'s case, and I think it at best doubtful that a thorough investigation at the time would have reached the conclusion that she had capacity.<sup>46</sup>

Thus, in discussing *E*'s advance directive, the courts considered the issue of capacity assessment retrospectively, and were more persuaded that *E* had lacked capacity at the time of making both advance directives.<sup>47</sup> They therefore concluded that she did not have the capacity to make decisions regarding medical intervention by forcible treatment.<sup>48</sup> This case demonstrates the ethical dilemmas inherent in advance directives, and that respect for autonomy in these circumstances can be a challenge for all parties involved.

## VII. WHEN SHOULD ADVANCE DIRECTIVES NOT BE UPHELD?

There is the notion that people's wishes will change over time, and that a person who initially wished to refuse a medical treatment may wish to receive other acceptable treatments. For example,

<sup>38</sup> *A Local Authority v E & Others* [2012] EWHC 1639 (COP), [2012] 6 WLUK 325 (*E*) [1].

<sup>39</sup> *Ibid.*

<sup>40</sup> *Ibid* [1], [31].

<sup>41</sup> *Ibid* [59], [65].

<sup>42</sup> Section 25 (2) (c) MCA 2005.

<sup>43</sup> *A Local Authority v E & Others* [2012] EWHC 1639 (COP), [2012] 6 WLUK 325 (*E*) [1] [ 68].

<sup>44</sup> *Ibid* 61].

<sup>45</sup> *Ibid* [69].

<sup>46</sup> *Ibid* [65] Jackson J.

<sup>47</sup> *Ibid* [70].

<sup>48</sup> *Ibid.*

Auckland makes the strong point that ‘As the directive may have been drafted a long time in advance it is possible that it may not, at the time of implementation, continue to represent the person’s values or priorities. The person may have found a religion; got married; or had children.’<sup>49</sup> However, it is questionable whether this is enough to render an advance directive invalid. Life-changing events are inevitable in any person’s life, so do we then include a clause in an advance directive to give effect in the event that there is a change of circumstances that invalidates the advance directive? Whilst such a clause would not be binding, in my view it could prove effective. Auckland’s view was witnessed in the court’s decision in *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam), [2003] 5 WLUK 168, where the person’s change of religion invalidated their advance directive. Nonetheless, it can be argued whether intervening events should render advance directives invalid when the person has not expressly changed the wording of their advance directive, and thus overriding their wishes could be seen as an infringement of their rights under Article 8(1) of the European Convention of Human Rights. It appears that the courts are inclined to place greater weight on any inconsistencies per Section 25(2) (c) MCA, or where it is clear that the person’s capacity is ambivalent at the time of making the advance directive. As Jackson J said in the case of *A Local Authority v E & Others* [2012] EWHC 1639 (COP), [2012] 6 WLUK 325 (E):

I consider that for an advance decision relating to life-sustaining treatment to be valid and applicable, there should be clear evidence establishing on the balance of probability that the maker had capacity at the relevant time. Where the evidence of capacity is doubtful or equivocal it is not appropriate to uphold the decision.<sup>50</sup>

### VIII. ADVANCE DIRECTIVES AND DEMENTIA

Advance directives in cases of dementia raise ethical challenges as to whether they should be

upheld. In my view, it is difficult to uphold an advance directive when the person who drafted it is now at a different stage in their life. In such a case, the wishes stipulated in their advance directive may not be applicable to the current circumstances of a person now suffering from dementia. Moreover, the advance directive no longer represents the person they are; their desires may have changed in contrast to what was previously drafted in their advance directive. As E. de Boer et al. observe, ‘Consequently, a situation may arise where there is a conflict between the current wishes of the person with dementia (expressed in words or behavior) and their former preferences as stated in the advance directive’.<sup>51</sup> I am of the view that a person’s advance directive should be respected. However, I am also of the view that it would not be conducive to a person in these circumstances to be bound by their previous wishes when their current situation requires a course of action different from the one previously stipulated in their advance directive. According to the Mental Capacity Act Code of Practice, ‘The Act does not spell out whether the person with dementia could invalidate their past decision by demonstrating changed attitudes after loss of capacity, for example by clearly demonstrating pleasure in life despite having made an advance decision based on a belief that they would find no value in a life with dementia.’<sup>52</sup> Walsh argues in favour of giving moral weight to the decisions of dementia patients who, she asserts, have had a transformative experience, as any choices made prior to that experience could not foresee that they would undergo such change.<sup>53</sup> As she succinctly puts it:

Preferences made after a transformative experience such as having dementia are legitimate and ought to be given moral weight in medical decision-making. As such preference changes are unpredictable, given the nature of transformative experience itself, they could not be fully considered by

<sup>49</sup> Auckland, n (14), 78.

<sup>50</sup> *A Local Authority v E & Others* [2012] EWHC 1639 (COP), [2012] 6 WLUK 325 (E) [55] Jackson J.

<sup>51</sup> E. de Boer et al. ‘Advance directives in dementia: issues of validity and effectiveness’ (2010) *International Psychogeriatrics*, 22:2, 201, 203.

<sup>52</sup> Mental Capacity Code of Practice

<[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/921428/Mental-capacity-act-code-of-practice.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf)> accessed 3 January 2023, para [5.39], p. 85.

<sup>53</sup> Emily Walsh, ‘Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives,’ (2020) *The American Journal of Bioethics*, 20:8, pp. 54, 55.

someone who is in a process of drawing up an advance directive.<sup>54</sup>

Walsh draws an interesting comparison between the preference changes of parents after having children and those of dementia patients.<sup>55</sup> She suggests that, while a parent's change of preference would be afforded moral weight, the same would not be deemed acceptable in the case of someone with dementia, '[W]here dementia patients' preference changes are not given moral weight and allowed to override the weight of their advance directive.'<sup>56</sup>

Auckland goes so far as to state that, 'Given the clear harm of tying someone with dementia to a decision that is no longer deemed in their best interests, however, it is difficult to justify upholding an advance directive where their capacity at the time of drafting was doubtful'.<sup>57</sup> She makes the further point that:

A more fundamental problem however remains. Given the dramatic changes of character that dementia can provoke, this raises the question of whether it is still right to uphold a directive where a person's values, priorities or lifestyle have changed so significantly since drafting the directive, that it is unclear whether the values which underpinned the decision have remained the same.<sup>58</sup>

## IX. CONCLUSION

The literature has shown that advance directives should not be binding in circumstances where the identity of the person has changed, where it is clear that there are inconsistencies, or where there has been a change of circumstances that render the advance directive no longer applicable. It has also shown the importance of giving moral weight to preference changes in demented patients. In my view, this demonstrates inclusiveness and respect for the person's self-determination. For example, in cases of dementia, the person is not the same person they were when they made the advance directive; and their wishes may well have changed over time. Thus, deeming an advance directive valid and binding in that situation may not be plausible. Whilst

it is important to respect the autonomy of the individual, it is also not appropriate to bind the patient to their advance directive in circumstances where doing so is clearly not appropriate.

Case law has also demonstrated that the wishes expressed in an advance directive cannot always be respected, irrespective of whether they go against the principle of autonomy. For example, if advance directives were to be binding in all circumstances, then they could also contradict the current position of the person, such as in the case of dementia patients who have undergone a transformative experience. Moreover, a person having renounced their religion is a clear indication that their previously expressed wishes to refuse any blood product may not be applicable to their present circumstances. If they are now observing a religion that does not prohibit blood transfusion, then there is no justifiable reason to uphold an advance directive that contradicts their best interest in a life-threatening situation. It is therefore evident that advance directives should not be binding in all circumstances, but rather, the courts should determine whether the inconsistencies that have arisen are an indication that the person's beliefs have become contrary to their advance directive and, if so, discard the advance directive and allow the clinician to provide a treatment in their best interest. It is justifiable to interfere with an advance directive when a person has clearly demonstrated that it cannot be valid and applicable to the proposed treatment in question.

It is apparent that there will always be challenges when the courts intervene in a person's advance directive because, after all, it represents their express wishes. However, it is also clear that the courts cannot uphold every advance directive merely because a person once expressed a particular wish, if they have since acted in ways which go contrary to their directive. It is, therefore, vital that an advance directive be drafted in such a way as to accord with the person's specific instructions in the event that they lose capacity and can no longer make decisions regarding their medical treatment. As Walsh succinctly puts it, '... one needs to ensure that

<sup>54</sup>Ibid. 55.

<sup>55</sup> Ibid pp.60,61.

<sup>56</sup> Ibid pp. 61.

<sup>57</sup> Auckland, n (14) 85

<sup>58</sup> Auckland, n (14) 75.



the interpretation of one's advance directive is relatively straightforward for medical professionals and loved ones.<sup>59</sup> The crux here lies in ensuring that there is no ambiguity in the drafting of the advance directive and that the person's intentions are clear in order to prevent the court from determining that the directive is inconsistent with their intentions or present circumstances. Moreover, as case law has demonstrated that unintentional acts or personal beliefs can have an impact on a person's advance directive, it is important that a person updates their advance directive should they be aware of any intentional change of circumstances such as conversion to a new religion. There is still a gap in the law regarding capacity assessment; it is highly recommended that the MCA implement a requirement for such in relation to advance directives because, in my view, this could avoid future disputes and enable certainty in establishing the validity of an advance directive. If a capacity assessor determines that a person lacks capacity, then clearly that person does not have the capacity to make an advance directive that refuses future medical treatments.

#### X. FINAL DISCUSSION

There are benefits to making an advance directive if it is drafted in accordance with the relevant sections of the MCA. Then, in effect, you have a legally binding document that enables you to plan your future medical treatment, and nobody can interfere with your decisions unless, as discussed here, you act in a way that is inconsistent with the advance directive, or it is not compliant with the formalities under Sections 25(5) and (6) in respect of life sustaining treatment. The ability to plan ahead and be in control of your future medical treatment gives you the autonomy to decide what happens to you at a later stage of your life, based on your specific written instructions, and for this reason I personally welcome the use of advance directives.

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<sup>59</sup> Walsh, n (53) 63

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