

Why and how sections 24-26 of the Mental capacity act 2005 on advance decisions need to be reformed

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ABSTRACT: In this paper, it is submitted that Sections 24-26 of the Mental Capacity Act 2005 have fallen short of achieving their goals, and should therefore be subject to focused reform. These statutory provisions were aimed at clarifying the scope of the pre-existing criteria used by common law to establish the existence, validity and applicability of advance refusals of treatment; and at making sure these criteria were applied coherently with the autonomy-based approach that informs the Act. However, the analysis of these Sections as well as of the relevant case law reveals the issues that prevent those objectives from being accomplished. By not introducing clear and explicit presumptions of validity and applicability of the advance decisions, and of capacity of the creator, this piece of law has not effectively tackled the courts' tendency to adopt a paternalistic approach towards precedent autonomy. Yet, these provisions have established a liability regime for those disregarding advance decisions, which clearly favours preservation of life over autonomy. Lastly, their wording, in some cases, seems to allow the revocation of the advance decision by incompetent patients. Accordingly, it is outlined how each of these flaws should be amended so as to bring Sections 24-26 in line with their legal premise: the primacy given to precedent autonomy.

KEYWORDS: Advance decisions to refuse medical treatment; mental capacity act 2005; precedent autonomy; self-determination; preservation of life.

SUMMARY: 1. Introduction – 2. Sections 24 – 26 MCA – 3. Why reform is needed – 4. Validity and Applicability: “wrong” presumption? Recommended amendments – 5. Capacity: lack of presumption? Time to be explicit – 6. Conclusion.

1. Introduction

Among other issues, the Mental Capacity Act 2005 (MCA) regulates advance decisions to refuse medical treatment (ADs or AD) in Sections 24-26. These provisions have been criticised by both those who endorse the moral authority of «precedent autonomy»¹, and

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¹ As pointed out by P. LEWIS, *Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?*, in *European Journal of Health Law*, 13, 2006, 220, this ex-

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those who challenge it. The analysis proposed hereinafter does not question such authority. Therefore, it does not consider whether ss. 24-26 MCA should be reformed in order to accommodate the main philosophical objections moved to this approach, namely the «personal identity and welfare problems»². Instead, the paper argues that some reform of these provisions is needed in order to enforce the legal authority of precedent autonomy in practice, therefore ensuring actual compliance with the right recognised to individuals to refuse medical treatments in advance.

The analysis starts by recalling the content of those provisions that should be involved in a reform process. It then turns the attention to the aim of Sections 24-26, and to why they have not successfully dealt with the pre-existing issues produced by a common-law conservative approach. Finally, it analyses these issues and the related flaws contained in the statutory provisions more in depth, and it recommends some interventions aimed at making ss. 24-26 effectively consistent with their legal premise.

2. Sections 24-26 MCA

Before considering whether and how Sections 24-26 of the Mental Capacity Act should be reformed, it is helpful to recall the content of their most relevant provisions in this regard. Advance decisions are anticipatory statements «made while a person is capable, which are intended to give effect to that person's wishes as to how he or she shall be treated or cared for after the loss of capacity»³.

According to Sections 24(1)(2), ADs can be made by competent adults⁴, and must specify - lay terms are accepted - the circumstances in which they apply as well as the treatment(s) to be refused⁵ once

pression is used by R. DRESSER, *Dworkin on Dementia: Elegant Theory, Questionable Policy*, in *The Hastings Center Report*, 25/6, 1995, 34, to refer to «projections of a person's autonomy interests into a future in which the person will no longer be able to make her own autonomous decisions».

² For the analysis of this issue, see P. LEWIS, *Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?*, cit., 219. For the related philosophical discussion, see A. MACLEAN, *Advance Directives, Future Selves and Decision-Making*, in *Medical Law Review*, 14/3, 2006, 291.

³ LORD CHANCELLOR'S DEPARTMENT, *Making Decisions*, Cm 4465 (London, 1999), [13], <http://webarchive.nationalarchives.gov.uk/+http://www.dca.gov.uk/family/mdecisions/introfr.htm#part2>, (last visited 13/09/2016).

⁴ As pointed out by P. LEWIS, *The Limits of Autonomy: Law at the End of Life in England and Wales*, in S. NEGRI (ed.), *Self-Determination, Dignity and End-of-Life Care. Regulating Advance Directives in International and Comparative Perspective*, Leiden-Boston, 2012, 223-224: «[W]hile in theory the pre-existing common law position could be applied to a competent child, this appears unlikely as competent children contemporaneously refusing life-saving treatment are always overruled, so advance refusals are simply likely to be overruled once a court is involved».

⁵ Advance decisions requesting treatments are not legally binding. See *R (Burke) v General Medical Council* [2005] EWCA Civ 1003, [50] [55]. However, they should be taken into account under s. 4(6)(a) MCA. This point is well summarised in the Code of Practice (CoP) [9.5]. See also the Explanatory Notes (EN) [84]. Past wishes of incompetent patients should be attributed even more weight after the decision of the Supreme Court in *Aintree v James* [2013] UKSC 67, [24], [45]. This position was recently reaffirmed, if not broadened, in *N* [2015] EWCOP 76 Fam, [27] [28] [30], and especially [32]; in this case, the Court of Protection held that the continuation of clinically assisted nutrition and hydration was not in the best interests of a patient in a minimally conscious state. See also A. RUCK KEENE, *Advance Decisions: getting it right?*, 2012, [33],

the patients have become incompetent. Provided that their creator retains capacity, advance decisions can be revoked or modified orally, unless the alteration concerns a decision to refuse life-sustaining treatments⁶.

In order to be legally binding⁷ advance decisions must be valid and applicable⁸. Section 25(2) states that ADs lose validity if: they are withdrawn; the creator has subsequently appointed one or more donees of a lasting power of attorney⁹, specifically endowed with the authority «to give or refuse consent to the treatment to which the advance decision relates»¹⁰; the author «has done anything else clearly inconsistent with the advance decision remaining his fixed decision»¹¹.

Sections 25(3) and (4) point out that advance decisions are not applicable if: at the time of making the decision the patient is still competent; the treatment at stake is not the one stated in the AD; «any circumstances specified in the advance decision are absent»¹²; it can be reasonably believed that there are circumstances which the creator «did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them»¹³. Moreover, Sections 25(5) and (6) have introduced what is likely to be the main innovation with pre-existing common law rules¹⁴; namely, in order to be applicable, advance refusals of life-sustaining treatment must comply with the following formalities: they must be accompanied by a statement whereby the author confirms that they are to apply «even if life is at stake»¹⁵; they must be in writing¹⁶ and signed by the patient or, when this is not feasible, by someone else¹⁷; the signature must be done in presence of a witness, who then signs the document herself¹⁸.

Section 26(1) confirms what was already established at common law: valid and applicable advance decisions have the same legal force of contemporaneous refusals of treatment¹⁹. Sections 26 (2) and (3) state that a person will not be liable for disregarding an AD if she was not satisfied about its existence, validity and applicability²⁰; whilst, the same person will escape liability for executing an invalid and inapplicable advance decision, only if she had «reasonable grounds for believing»²¹ that it was in

http://www.39essex.com/content/wp-content/uploads/2012/12/advance_decisions_paper_ark_december_2012.pdf, (last visited 12/09/2016).

⁶ MCA ss. 24(3)(4)(5). The meaning of life-sustaining treatment is stated in s. 4(10) MCA. See also CoP [9.25] and EN [89].

⁷ For exceptions, see CoP [9.37].

⁸ MCA, ss.25(1)(a)(b).

⁹ MCA, ss. 9-14.

¹⁰ MCA, s. 25(2)(b).

¹¹ MCA, s. 25(2)(c).

¹² MCA s. 25(4)(b).

¹³ MCA, s. 25(4)(c).

¹⁴ E. JACKSON, *Medical Law. Text, Cases, and Materials*, (3rd ed.), Oxford, 2013, 247-248.

¹⁵ MCA, s. 25(5)(a).

¹⁶ MCA, s. 25(6)(a).

¹⁷ MCA, s. 25(6)(b).

¹⁸ MCA, ss. 25(6)(c)(d). This rule was applied in *An NHS Trust v D* [2012] EWHC 885 (COP).

¹⁹ EN [84], [91].

²⁰ CoP [9.58]. If instead the person was satisfied, the CoP [9.57] points out that «[f]ailure to follow an advance decision ... could lead to a claim for damages for battery or a criminal charge for assault». These consequences had already been established at common law, see *Airedale NHS Trust v. Bland* [1993] AC 789, [882].

²¹ EN [91]. See also CoP 9.59.

fact valid and applicable. Furthermore, this section makes clear that, while a decision is sought from the Court of Protection on any issue concerning the AD, a person is entitled to provide life-saving treatments, or to do «any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition»²².

3. Why reform is needed

The aim of Sections 24-26 was «to codify and clarify the current common law rules, integrating them into the broader scheme of the Act»²³. According to pre-existing case law, as long as individuals are competent, and their decision is informed and voluntary, they have an absolute right to refuse any treatment for whatever reason, and even for no reason at all²⁴. Hence, provided that «all necessary steps have been taken to be sure that this is what he or she wants»²⁵, the state acknowledges the primacy of the patients' self-determination over other fundamental interests, most notably preservation of life²⁶. This 'arrangement' was extended by the Courts to advance refusals of treatments²⁷. Yet, in practice, it is generally more problematic to enforce advance than contemporaneous refusals. Indeed, in the first scenario, it may be more difficult for the physician to verify whether the patient had capacity when she made the advance decisions²⁸, or whether the situation described, perhaps in generic terms, in the ADs was meant to cover the actual circumstances in which a decision on whether to administer a specific treatment should be taken²⁹. Accordingly, the frequent uncertainty³⁰ that characterises advance decisions was likely to justify the strict scrutiny of their validity and applicability carried out by both healthcare professionals and courts³¹. It seems, therefore, understandable that, especially in case of advance refusals of life-sustaining treatments, the state's interest in protecting the lives of incompetent patients was given somewhat more weight than in cases of contemporaneous refusals³². However, as some commentators have noticed³³, the broadness of the criteria adopted to carry out this scrutiny was such as to allow the courts to embrace a paternalistic ap-

²² MCA, ss. 26(5)(a)(b).

²³ EN [84].

²⁴ *Re M.B. (Medical Treatment)* [1997] 2 F.L.R. 426, [432]. In *Pretty v. United Kingdom* (2002) 35 EHRR 1, [63], the ECtHR held that this right is protected under Art. 8(1) of the ECHR.

²⁵ *Bland*, cit., [892].

²⁶ *Ibidem*, [846]. See also *Re T (Adult Refusal of Treatment)* [1993] Fam 95, [112].

²⁷ *Re T*, cit., [103]; *Bland*, cit., [864]; *Re C (Adult Refusal of Treatment)* [1994] 1 All ER 819, [825]; *Re AK (medical Treatment: Consent)* [2001] 2 FCR 35, [41].

²⁸ A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, in *Medical Law Review*, 16/1, 2008, 13.

²⁹ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, in *Medical Law Review*, 68/6, 2005, 959.

³⁰ E. JACKSON, op. cit., 905-906.

³¹ *Re T*, cit., [112], [103]: the «careful examination» required to establish whether «the individual is exercising that right» [112], in the case of «anticipatory choice», must be even more careful, as it is subject to «two major ifs:» «clearly established and applicable in the circumstances» [103].

³² S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 960.

³³ *Ibidem*, 959, 966-977; See also A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 3, 10-21.

proach, whereby the aforementioned priority of autonomy was often recognised in principle, but undermined in practice³⁴. Had Sections 24-26 been successful in clarifying those criteria, they could have restrained this controversial tendency adopted at common law. However, as the remaining part of the essay attempts to show, these provisions have fallen short of achieving their goal. They have not tackled some of the pre-existing issues (i.e. absence of presumptions of validity, applicability and capacity), or they have, in fact, worsened them³⁵ (i.e. doubts on revocation of advance decisions by incompetent patients; uneven liability regime). Thus, unless the legislature intends to explicitly revise the legal 'arrangement' outlined above with regard to advance refusals of medical treatments, focused reform of ss. 24-26 MCA is needed to reaffirm the legal primacy of precedent autonomy, not only in principle³⁶ but also in practice. This is also required to ensure compliance with the European Convention on Human Rights, especially after its incorporation into domestic law by means of the Human Rights Act 1998³⁷.

4. Validity and applicability: "wrong" presumption? Recommended amendments

Before the entry into force of the Mental Capacity Act 2005, the courts had been called to establish the validity and applicability of advance refusals of treatments in few occasions. Apart from one case³⁸, in which the refusal was exceptionally «precise, recent, and unambiguous»³⁹, the criteria set out by Lord Donaldson in *Re T*⁴⁰ did not prove to be clear enough to guarantee an autonomy-based interpretation of advance decisions⁴¹; quite the contrary. Indeed, according to this authority, any doubt concerning the validity of the AD «falls to be resolved in favour of the preservation of life»⁴². This approach was followed by the High Court in *HE v A Hospital NHS Trust*⁴³. This case concerned a gravely ill young Jehovah's Witness who had written an advance decision refusing blood transfusion in 'any circumstances'. By the time this treatment became necessary she had lost capacity, but her father applied to the court for a declaration that carrying out the transfusion was lawful despite her

³⁴ For a discussion of the reasons behind this courts' approach, see *Ibidem*, 961.

³⁵ *Ibidem*, 982.

³⁶ *Ibidem*, 981. It could also be argued that, despite the alleged preference given to self-determination – see CoP [9.36], the choice to invalidate ADs in presence of a subsequent LPA with the same scope of the former – see MCA s. 25(2)(b) - indicates an implicit attention to welfare interests. Indeed, under s. 9(4)(a), it is established that this attorney can make only decisions that comply with the best interests of the patient. The same could be held with regard to basic care. Though, the Act does not expressly deny the possibility to refuse it, the CoP [9.28] does so.

³⁷ E. WICKS, *The Right to Refuse Medical Treatment Under The European Convention On Human Rights*, in *Medical Law Review*, 9/1, 2001, 27.

³⁸ *Re AK*, supra, footnote 27. In this case, a 19-year-old patient suffering from motor neurone disease was terminally ill and could only communicate by moving one eyelid. He asked that artificial ventilation would be stopped two weeks after he lost the ability to communicate. He then confirmed his wish after a doctor had explained the consequences of his decision to him.

³⁹ E. JACKSON, op. cit., 906.

⁴⁰ *Re T*, cit., [112], [115-116].

⁴¹ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 966, 971.

⁴² *Re T*, cit., [112].

⁴³ *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam).

advance decision. To support his request, he argued that his daughter «had rejected that faith and had become engaged to a Muslim, that she had not attended Jehovah's Witness' meetings or services and that this had been confirmed by her»⁴⁴. Munby J held that, «once there is some real reason for doubt, then it is for those who assert the continuing validity and applicability of the advance directive to prove that it is still operative»⁴⁵. If they cannot make it, then the presumption in favour of preservation of life prevails⁴⁶.

However, the criteria laid down in the MCA do not seem able to change course. The example given in the Explanatory Notes⁴⁷ to clarify the meaning of s. 25(2)(c) is clearly based on the facts of *HE v A Hospital NHS Trust*. Moreover, this provision has been criticised for being even more ambiguous than the position expressed at common law. Indeed, as pointed out by Maclean, this section «makes no mention of the need for capacity and it may, therefore, be arguable that it applies to the person's behaviour even when he or she lacks the capacity to revoke the advance directive under s. 24(3)»⁴⁸.

As for 'applicability', though s. 25(4)(c) states that the decision on whether there are circumstances not anticipated by the patient that could have changed his mind had she been aware of them must be based on «reasonable grounds», it remains unclear «how it can and should be determined whether such reasonable grounds exist in a given situation»⁴⁹. The guidance provided by the Code of Practice⁵⁰ does not seem enough to define the scope of this provision, which remains «potentially extremely broad»⁵¹. The debate⁵² concerning the possibility to apply this section to cases of demented patients who, despite having written an advance refusal of life-sustaining treatments when they were competent, appear to enjoy life shows the uncertainty inherent in its wording.

Further evidence that the criteria used in the Act to scrutinise validity and applicability of advance decisions have implemented the paternalistic approach towards precedent autonomy highlighted in *Re T* and *HE* is provided by the uneven regime of liability set out in ss. 26(2) and (3)⁵³. The fact that the obligation to «demonstrate that their belief was reasonable» and «based on reasonable grounds»⁵⁴ is placed only upon healthcare professionals who execute an invalid AD, while those who do not apply a valid one can avoid liability simply by presenting a genuine doubt about its validity and applicability⁵⁵, indicates how the balance tips in favour of preservation of life, instead of autonomy⁵⁶.

⁴⁴ A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 7.

⁴⁵ *HE*, cit., [43]. See also *Ibidem*, [23], [46 v].

⁴⁶ *Ibidem*, [43],[46 (vii)].

⁴⁷ EN [87].

⁴⁸ A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 20. See also S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 974. See also A. RUCK KEENE, op. cit., [26.1].

⁴⁹ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 972.

⁵⁰ CoP [9.43].

⁵¹ E. JACKSON, op. cit., 247.

⁵² S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 974.

⁵³ *Ibidem*, 960.

⁵⁴ CoP [9.59].

⁵⁵ CoP [9.58]. Although paragraph [9.53] recommends that notes are taken to explain why the advance decision was not followed, it does not require that the explanation relies on reasonable grounds: the existence of a

The recommendations provided in the Code of Practice⁵⁷ aimed at reducing the likelihood of questioning the validity and applicability of advance decisions have not proved adequate to address the concern that still exists⁵⁸ about ensuring respect for these expressions of self-determination.

It is maintained that each of these issues could be dealt with effectively by making the following amendments to ss. 24-26 MCA.

- Stating clearly that Section 25(2)(c) only refers to actions carried out by competent patients. This clarification would bring the provision in line with both s. 24(3), and s. 25(2) (a) (b). As noted by Ruck Keene, «[a]s a matter of logic, if one no longer has the capacity to withdraw a decision [s. 24(3)], one can no longer have the capacity to “unfix” that decision»; moreover, «both of the other limbs of s.25(2) clearly relate to circumstances pertaining whilst the person has the requisite capacity (the first limb being to withdraw the advance decision, the second being to grant an LPA).»⁵⁹
- Rejecting the possibility to find advance decisions inapplicable because of the behaviour held by demented patients⁶⁰. To override a decision taken by competent patients to refuse a specific treatment, because their demented selves express the desire to do otherwise, would excessively undermine the authority given to precedent autonomy in favour of paternalism⁶¹. Furthermore, by giving relevance to the argument whereby the patient had not considered the possibility that dementia could change his/her attitude towards illness and treatments, advance decisions would be «subject to an extensive test of the patient’s motives for refusing treatment»⁶². Any such test would have the undesirable consequence of placing a disproportionately higher threshold to assess the capacity of those making advance decisions compared to the one applied to contemporaneous refusals⁶³.

doubt on the validity and applicability of the AD would be sufficient to avoid liability. See also A. RUCK KEENE, op. cit., [34.3].

⁵⁶ A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 21. See also S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 960.

⁵⁷ I.e. CoP [9.16], [9.29].

⁵⁸ See HOUSE OF LORDS, SELECT COMMITTEE ON THE MENTAL CAPACITY ACT 2005. *Report of Session 2013-2014, Mental Capacity Act 2005: post-legislative scrutiny (March 2014)*, 76-77, <http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm>, (last visited 13/09/2016).

⁵⁹ A. RUCK KEENE, op. cit., [27.2]. See also A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 19. See supra, page 3.

⁶⁰ Introducing this exception would be extremely problematic: see P. LEWIS, *Medical Treatment of Dementia Patients at the End of Life: Can the Law Accommodate the Personal Identity and Welfare Problems?*, cit., 230-233.

⁶¹ A. RUCK KEENE, op. cit., [28].

⁶² S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 976-977. See *Ibidem*, where the author adds that, «if upholding advance decisions in the particular context of dementia is regarded as undesirable and counter-intuitive, the consequence should not be to suggest that advance decisions should be overridden, by whichever means, but rather to create awareness of the consequences of such decisions and to invite the patient to consider whether or not he/she wants the advance directive to be a binding document, with all the consequences that entails, or instead wants to provide no more than an instrument that informs proxy decision-makers of his/her preferences, while leaving the final decision to them.»

⁶³ A. RUCK KEENE, op. cit., [17.2].

- Adjusting the liability regime by bringing Section 26(2) into alignment with Section 26(3). This could be done easily by requiring “reasonable grounds” to avoid liability also for disregarding an existent, valid and applicable advance decision⁶⁴. A requirement that could be met by asking the healthcare professionals involved to take documented steps «to investigate prima facie concerns»⁶⁵. Instead, the current system seems to rely on the assumption that, especially with regard to life-saving treatments, overriding an autonomous refusal by mistake is less harmful than withholding or withdrawing treatment to a patient because his/her advance decision was erroneously believed to be existent, valid and applicable⁶⁶. However, as Michalowski has pointed out, «the idea that life is always preferable is exactly what patients who make advance decisions refusing life-saving or life-sustaining treatment doubt. They see a preservation of their life in the circumstances in which they want the advance directive to apply, or by the means they reject, as more harmful than death.»⁶⁷
- A decisive amendment would be to introduce a presumption of validity and applicability, at least for advance refusals of life-saving treatments⁶⁸. In the MCA 2005 there is no clear indication as to who carries the burden of proof with regard to the continuing validity and applicability of advance decisions⁶⁹. The *HE* case shows how this omission has allowed the courts to hold on to a paternalistic approach that, as previously explained, is clearly at odds with the Act’s intention «to give patients,

⁶⁴ S. MICHALOWSKI, *Trial and Error at the End of Life – No Harm Done?*, in *Oxford Journal of Legal Studies*, 27/2, 2007, 261. The author maintains that this was the approach followed by the judges in the Canadian ruling *Malette v Shulman*, (1990) 67 DLR (4th), 321. In this case, an unconscious Jehovah’s Witness was given a life-saving blood transfusion, despite carrying a card stating that she would refuse such treatment under any circumstances. According to S. MICHALOWSKI, *Ibidem*, 262, «[the] court held that the administration of blood transfusion amounted to a battery, even though the physician had had doubts concerning the validity of the card, as the court thought that in the presence of an unequivocal and unqualified treatment refusal it was the responsibility of the physician who nevertheless administered treatment to show reasonable grounds why the patient did not want the refusal to apply to the particular treatment situation. The court would thus presumably take into account a physician’s mistake, but only if it was reasonable.»

⁶⁵ A. RUCK KEENE, *op. cit.*, [34.3].

⁶⁶ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, *cit.*, 961. The author points out that this was also the argument followed by Chief Justice Rehnquist in *Cruzan v Director, Missouri Department of Health*, 110 S Ct 2841 (1990), 285. Following a car accident, Nancy Cruzan was diagnosed with persistent vegetative state, and given artificial nutrition and hydration. Her parents filed for and received a court order for the treatments to be withdrawn. The case reached the US Supreme Court, which upheld the ruling of the Missouri Supreme Court that had denied the withdrawal of life-sustaining treatments because of the lack of «clear and convincing evidence» ([261]) about the patient’s intention to refuse them. Michalowski, instead, endorses the reasoning set out by Justice Brennan in his dissenting opinion, in which he argued that: «from the point of view of the patient, an erroneous decision in either direction is irrevocable» and that, «[e]ven a later decision to grant him his wish cannot undo the intervening harm.»

⁶⁷ *Ibidem*. In S. MICHALOWSKI, *Trial and Error at the End of Life – No Harm Done?*, in *Oxford Journal of Legal Studies*, *cit.*, 262, the same author maintains that «this approach strikes the better balance between the interest of the patient in having an advance refusal respected, and his/her own as well as the state’s interest in preserving life where reasonable grounds exist to assume that the patient had not made an autonomous decision against life-saving treatment.»

⁶⁸ It was also recommended by the LAW COMMISSION, *Report No. 231. Mental Incapacity (HMSO 1995)*, [5.29], [5.30], https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/228896/0189.pdf, (last visited 14/01/2016)

⁶⁹ See A. RUCK KEENE, *op. cit.*, [23].

while competent, the opportunity to make binding decisions for the time of their future possible incompetence, without having to reply on the good will of others.»⁷⁰.

5. Capacity: lack of presumption? Time to be explicit

With regard to Sections 24-26 MCA, another crucial issue concerns the applicability to advance decisions of the general presumption of capacity set out in Section 1(2). While the provisions of the Act do not expressly reaffirm it, the CoP [9.8] is ambiguous in this regard. On the one hand, it extends the applicability of this presumption also to ADs; on the other hand, it seems to apply the exemption from liability granted to those who ignore these decisions, because they have doubts about their validity and applicability⁷¹, also to cases in which the doubts concern the existence of the advance decision, and, therefore, potentially also the capacity of the creator⁷².

This ambiguity could be one of the reasons⁷³ that enabled Peter Jackson J, in *A Local Authority v E*⁷⁴, to embrace a similar interpretation of the law. Indeed, contrary to what held by Munby J in *HE v A Hospital NHS Trust*⁷⁵, he seemed to hold that «the burden of proof is upon the maker (or those ‘supporting’ the maker) to establish capacity»⁷⁶.

Similarly to what observed for validity and applicability, this approach towards capacity is detrimental to the primacy assigned to autonomy and self-determination in this context. It would therefore be advisable to reform ss. 24-26 MCA so as to explicitly apply the presumption of capacity set out in Section 1 also to advance refusals of treatment⁷⁷. Undoubtedly, such refusals, «are less susceptible to control than contemporaneous treatment refusals, where the physician can observe the patient and has the opportunity to detect factors that might cast doubts on the patient’s competence»⁷⁸. However, this intrinsic flaw⁷⁹ of ADs could be effectively dealt with by introducing a «formal assessment of competency»⁸⁰ to be carried out at the time of making the advance decision. As pointed out by Maclean, «the relatively minor infringement of autonomy in requiring medical advice

⁷⁰ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 971. See A. RUCK KEENE, op. cit., [23].

⁷¹ MCA, s. 26(2).

⁷² According to MCA, s. 24(1) capacity is a necessary condition for the existence of advance decisions.

⁷³ The fact that the patient was suffering from a mental disorder is likely to be another factor that influenced the decision on capacity. See MCA, ss. 2(1) and 3(1).

⁷⁴ *A Local Authority v E* [2012] EWHC 1639 (COP), [55]. In this case an anorexic woman attempted twice to execute an advance decision refusing force-feeding.

⁷⁵ *HE*, cit., [20 (iii)] [23].

⁷⁶ A. RUCK KEENE, op. cit., [19.6].

⁷⁷ See *Ibidem*, [19.2], in which the author argues that «reflecting the first principle of the Act (sec. 2(2)), and as set down in the Code of Practice (para. 9.8), the starting presumption should be that the person had the capacity to make an advance decision. Logically, therefore (and in the line with the general approach) the burden should rest upon the person asserting that there was a lack of capacity at the material time to establish that fact. Where the evidence is contradictory and insufficient, the operation of the presumption/burden should mean that the person should be held to have the relevant capacity».

⁷⁸ S. MICHALOWSKI, *Advance Refusals of Life-Sustaining Medical Treatment: The Relativity of an Absolute Right*, cit., 965. See also supra page 4.

⁷⁹ See *Ibidem*.

⁸⁰ A. MACLEAN, *Advance Directives and the Rocky Waters of Anticipatory Decision-Making*, cit., 14.

would be more than justified by the enhanced security of the advance directive regarding what is a fundamental life choice.»⁸¹

It has been noted that adding formalities would put people off from making advance decisions⁸². However, empirical research⁸³ suggests that others are the key barriers that discourage people from undertaking this process. Among such obstacles there are their concerns about advance decisions' effectiveness⁸⁴, which would most likely be reduced by establishing a mechanism to assess capacity in advance.

6. Conclusion

The function of Sections 24-26 MCA was to clarify the scope of the pre-existing criteria used by common law to establish the existence, validity and applicability of advance refusals of treatment, and to make sure these criteria were applied coherently with the autonomy-based approach that informs the Act. Unfortunately, these norms have not accomplished their purpose; therefore it would be advisable to modify them.

To sum up, with regard to validity and applicability, Section 25 should spell out that the inconsistent behaviour envisaged in Subsection (2)(c) does not refer to incompetent patients; similarly, Subsection (4)(c) should make clear that the unanticipated circumstances cannot comprise the unexpected conduct of patients suffering from dementia. Moreover, this Section should feature a presumption of validity and applicability in favour of advance decisions, which would also cause an amendment of Section 26 in order to qualify the reasons needed to escape liability for not complying with a valid AD. Yet, with regard to capacity, the general presumption stated in Section 1(2) should be expressly restated for advance decisions, though it could be subordinate to a preventive assessment.

In general, any effort to reform these provisions should place great emphasis on the increasing relevance given to past wishes of incompetent patients by the judiciary. Following the pivotal case *Aintree v James*⁸⁵, the Court of Protection has recently reaffirmed that, in this context, «the central objective is to avoid a paternalistic approach and to ensure that the incapacitous achieve equality with the capacitous»⁸⁶.

⁸¹ *Ibidem*, 15.

⁸² See *Ibidem*, 11.

⁸³ S. WILKINSON, *An Analysis of Calls to the Compassion in Dying End-of-Life Rights Information line, Executive Summary*, in <http://compassionindying.org.uk/wp-content/uploads/2014/12/Executive-Summary-Analysis-of-Calls-to-CID-InfoLine.pdf> (last visited 12/09/16).

⁸⁴ See *Ibidem*. Other factors appear to be: «not understanding legal issues»; «problems with professionals», for instance GPs who are not willing to support patients in this regard; «translating their wishes into a formal document».

⁸⁵ See *supra*, footnote 5.

⁸⁶ *N* [2015] EWCOP 76 Fam, [30]. See *supra*, footnote 5.