Advance Decisions: getting it right?

A: Introduction

1. The provisions relating to the existence, validity and applicability of advance decisions, and especially those relating to life-sustaining treatment, are some of the most important in the Mental Capacity Act 2005 (‘MCA 2005’). The penalties for failing to comply with the procedural requirements can result in the overriding by the Court of what may appear to be clear and strongly-held views expressed by P before the onset of incapacity.

2. The importance of getting advance decisions right has only been emphasised in a series of recent cases where such decisions have been placed under the microscope. This paper examines the statutory framework in light of those cases, with a particular reference to the extent to which the Courts are properly adhering to the principles enshrined in balance of the MCA 2005 when they come to consider advance decisions to refuse life sustaining treatment.

B: The background

3. Before turning to the statutory framework enshrined in ss.24-6 MCA 2005, it is instructive to review the position reached at common law, which can be done primarily by reference to two cases.

4. In Re AK (Adult Patient) (Medical Treatment: Consent) [2001] 1 FLR 129, Hughes J (as he then then was) reviewed the authorities, and summarised the position thus:

   “Accordingly, the first principle of law which I am satisfied is completely clear, is that in the case of an adult patient of full capacity his refusal to consent to treatment or care must in law be observed. It is clear that in an emergency a doctor is entitled in law to treat by invasive means if necessary a patient who by reason of the emergency is unable to consent, on the grounds that the consent can in those circumstances be assumed. It is, however, also clearly the law that the doctors are not entitled so to act if it is known that the patient, provided he was of sound mind and full capacity, has let it be known that he does not consent and that such treatment is against his wishes. To this extent an advance indication of the wishes of a patient of full capacity and sound mind are effective. Care will of course have to be taken to ensure that such anticipatory declarations of wishes still represent the wishes of the patient. Care must be taken to investigate how long ago the expression of wishes was made. Care must be taken to investigate with what knowledge the expression of wishes was made. All the circumstances in which the expression of wishes was given will of course have to be investigated.”
5. In *HE v A Hospital NHS Trust*, Munby J (as he then was) had cause to consider a (pro forma) “Advance Medical Directive/Release” signed by a young woman, AE, whilst she was a Jehovah’s witness, which sought to refuse the transfusion or blood or primary blood components in absolute and irrevocable terms. On an urgent application brought by a treating NHS trust, which wished to administer a blood transfusion, to AE, the Court had to decide whether the advance directive was valid and applicable. Munby J noted (paragraph 19) that:

“Some propositions are, in my judgment, now so well established in our law as no longer to require either justification or elaborate citation of authority. They are:

A competent adult patient has an absolute right to refuse consent to any medical treatment or invasive procedure, whether the reasons are rational, irrational, unknown or non-existent, and even if the result of refusal is the certainty of death. I agree with Professor Andrew Grubb’s observation (see [2002] Med L Rev 201 at 203) that:

‘English law could not be clearer. A competent adult patient once properly informed, has the unassailable legal right to refuse any or all medical treatment or care.’

Consistently with this, a competent adult patient’s anticipatory refusal of consent (a so-called ‘advance directive’ or ‘living will’) remains binding and effective notwithstanding that the patient has subsequently become and remains incompetent.

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.”

6. Munby J went on to analyse certain specific aspects of the law governing advance directives, summarising his views as follows, in a passage which bears setting out as representing the lay of the land as at the point when the MCA 2005 was enacted:

“The law – summary

[46] So far as is material for present purposes, I can accordingly summarise the law as follows:

1. There are no formal requirements for a valid advance directive. An advance directive need not be either in or evidenced by writing. An advance directive may be oral or in writing.

2. There are no formal requirements for the revocation of an advance directive. An advance directive, whether oral or in writing, may be revoked either orally or in writing. A written advance directive or an advance directive executed under seal can be revoked orally.

3. An advance directive is inherently revocable. Any condition in an advance directive purporting to make it irrevocable, any even self-imposed fetter on a patient’s ability to

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1 [2003] 2 FLR 408.
revoke an advance directive, and any provision in an advance directive purporting to impose formal or other conditions upon its revocation, is contrary to public policy and void. So, a stipulation in an advance directive, even if in writing, that it shall be binding unless and until revoked in writing is void as being contrary to public policy.  

4. The existence and continuing validity and applicability of an advance directive is a question of fact. Whether an advance directive has been revoked or has for some other reason ceased to be operative is a question of fact.

5. The burden of proof is on those who seek to establish the existence and continuing validity and applicability of an advance directive.

6. Where life is at stake the evidence must be scrutinised with especial care. Clear and convincing proof is required. The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.

7. If there is doubt that doubt falls to be resolved in favour of the preservation of life.”

7. These decisions must be read alongside the principles established in the Bland case governing the approach to the maintenance of life-sustaining treatment to those in a PVS, namely that:

7.1. the principle of the sanctity of life is fundamental;

7.2. that principle is not, however, absolute and may yield in certain circumstances, for example to the principle of self-determination;

7.3. a decision whether ANH treatment should be initiated or withdrawn must be determined by what is in the best interests of the patient;

7.4. in the great majority of cases the best interests of the patient were likely to require that the treatment should be given;

See also paragraph 39. On this basis, Munby J found that paragraph 2(d) of the directive in question was void as being contrary to public policy.

In the case before him, Munby J found that AE had revoked the advance directive she had made by rejecting her faith as a Jehovah’s Witness and converting to be a Muslim, as it destroyed very assumption upon which it was based (paragraph 49). Even if he were to be wrong in that, he held, there must be considerable doubt as to whether the advance directive was still valid and applicable, doubts which had to be resolved in favour of the preservation of life in circumstances where (absent a valid advance directive) the only answer to the question of what AE’s best interests required was that she have the blood transfusions recommended by the clinicians.

7.5. there was a category of case in which the decision whether to withhold treatment would be made by weighing up relevant and competing considerations, but

7.6. such an approach was inappropriate in the case of Anthony Bland as the treatment had no therapeutic purpose and was “futile” because he was unconscious and had no prospects of recovery.

8. They must also be read alongside two further principles that had been established at common law:

8.1. that, whilst a person did not have a right to ask for and be given treatment which constituted a positive act to assist in their suicide, they could refuse the provision or continuation of life-sustaining treatment even when the inevitable consequence was death;⁵

8.2. whilst an advance directive could request rather than refuse treatment, the principle that a person had the right to refuse treatment did not carry with it as a corollary that the person has a right to demand a specific treatment, whether at the time or in advance.⁶

9. Before coming to the MCA 2005, we might note that it is far from universally accepted that advance decisions should be determinative. To take the examples of two of our closest neighbours:

9.1. the Adults with Incapacity (Scotland) Act 2000 does not include any equivalent of ss.24-6; by s.1(4)(a), a person proposing to intervene in the affairs of an incapacitated adult must take account of “the present and past wishes and feelings of the adult so far as they can be ascertained by any means of communication, whether human or by mechanical aid (whether of an interpretative nature or otherwise) appropriate to the adult,” but the ultimate question of what shall be done is to be

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⁵ This principle was upheld by the ECHR in Pretty v United Kingdom (2002) 35 EHRR 1 at paragraph 63: “In the sphere of medical treatment, the refusal to accept a particular treatment might, inevitably, lead to a fatal outcome, yet the imposition of medical treatment, without the consent of a mentally competent adult patient, would interfere with a person's physical integrity in a manner capable of engaging the rights protected under Article 8(1) of the Convention. As recognised in domestic case law, a person may claim to exercise a choice to die by declining to consent to treatment which might have the effect of prolonging his life.”

⁶ See the judgment of the Court of Appeal in R (Burke) v General Medical Council [2006] QB 273: “55 As we understand Munby J’s judgment, he considered that in this situation [i.e. where a patient’s wish that ANH be continued might conflict with the doctor’s view that this is not clinically indicated] the patient's wish to receive ANH must be determinative. We do not agree. Clearly the doctor would need to have regard to any distress that might be caused as a result of overriding the expressed wish of the patient. Ultimately, however, a patient cannot demand that a doctor administer a treatment which the doctor considers is adverse to the patient's clinical needs. This said, we consider that the scenario that we have just described is extremely unlikely to arise in practice.”
determined by the intervener, who must be satisfied “that the intervention will benefit the adult and that such benefit cannot reasonably be achieved without the intervention;”

9.2. a similar approach can be found in France, where “directives anticipées” relating to the withdrawing/withholding of treatment must be taken into account by the doctor, but they are not binding; they are also time-limited to three years, and must be renewed thereafter.

10. The approach taken in Scotland and France undoubtedly reflects (at least in part) the different legal traditions of those two countries. However, one can detect even in this jurisdiction an understandable queasiness on the part of the judiciary as to the implications of an ‘absolutist’ approach to advance decisions. This underpins, in particular, the concern expressed to ensure that at the time that the decision was made the patient knowingly and freely intended that it would apply to the situation that would confront them in the future. Moreover, as Munby J noted in a footnote to his decision in HE, “exceptionally difficult moral, ethical and legal questions … may have to be addressed when a previously competent patient is in the ‘twilight’ position of having lost his capacity to decide whether or not to accept medical treatment but nonetheless remains able, to a greater or lesser extent, to express his wishes and feelings. Is such a patient to be held to his advance directive even if it appears to conflict with his current (incompetent) wishes and feelings?”

C. The MCA 2005

11. The common law has now been “refined” by passage of the MCA 2005, which makes statutory provision for advance decisions to refuse treatment in ss.24-6. It is perhaps – as a side-note – worth recalling that, at the early stages of the tortuous process by which the MCA was ultimately enacted, the Government did not

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7 Section 1(2). Section 1(3) also requires that the intervention be the least restrictive option.
9 Albeit that, as noted in Mason and McCall Smith’s Law and Medical Ethics (8th Edition, OUP 2011), citing Dworkin’s Life’s Dominion, it could arguably be said that the person who drafts an advance decision and the incapacitated person who benefits from it are effectively two different persons.
11 W v M [2012] 1 WLR 1653, at paragraph 65, per Baker J.
12 Not ‘directives,’ the term most commonly used under the common law. The shift in language and emphasis is interesting, placing the focus squarely upon the decision that the person must take; it is also in line with the ethos of the MCA 2005 which is concerned with P’s capacity to take specific decisions at specific points in time (and as to P’s best interests in the event that that capacity is lacking).
intend to place advance decisions on a statutory footing, proposing instead that they should continue to be governed by the common law.\textsuperscript{13} This position was, ultimately, reversed, and matters placed on a statutory footing albeit, as we shall see, in such a way as to leave substantial areas of ambiguity for judicial resolution.

12. I will analyse ss.24-6 in some detail, and in light of the glosses put upon it by three recent cases: \textit{A Local Authority v E},\textsuperscript{14} \textit{X Primary Care Trust v XB}\textsuperscript{15} and \textit{An NHS Trust v D},\textsuperscript{16} as well as the wider discussion of the issues concerning the withdrawal of life-sustaining treatment in \textit{W v M [2012] 1 WLR 1653}. I will proceed in stages, thus:

12.1. the definition of an advance decision;

12.2. establishing capacity to make an advance decision at the time, and in retrospect;

12.3. conditions for validity;

12.4. conditions for applicability, looking first at the definition of an advance decision, then as to questions concerning capacity;

12.5. the effect of an advance decision;

12.6. doubt and seeking the assistance of the Court.

\textit{Definition of an advance decision}

13. An “advance decision” has a specific statutory meaning, provided for in s.24(1), namely:

\begin{quote}
\textit{a decision made by a person (‘P’) after he has reached 18 and when he has capacity to do so, that if—}
\end{quote}

\textsuperscript{13} See paragraph 20 of “Making decisions: the government’s proposals for making decisions on behalf of mentally incapacitated adults; a report issued in the light of responses to the consultation paper Who Decides?”: “Given the division of opinion which exists on this complex subject and given the flexibility inherent in developing case law, the Government believes that it would not be appropriate to legislate at the present time, and thus fix the statutory position once and for all. The Government is satisfied that the guidance contained in case law, together with the Code of Practice Advance Statements about Medical Treatment published by the British Medical Association, provides sufficient clarity and flexibility to enable the validity and applicability of advance statements to be decided on a case by case basis. However, the Government intends to continue to keep the subject under consideration in the light of future medical and legal developments.”

\textsuperscript{14} [2012] EWHC 1639 (COP).

\textsuperscript{15} [2012] EWHC 1390 (Fam).

\textsuperscript{16} [2012] EWHC 885 (COP).
(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.”

14. The Act does not specify the terms in which a person is required to set out their decision; indeed, s.24(6) makes clear that a decision can be regarded as “specifying a treatment or circumstances even though it is expressed in layman’s terms” (s.24(2)). Chapter 9 of the Code of Practice accompanying the MCA 2005 suggests that it is helpful to include the following information:

14.1. full details of its maker, including date of birth, home address and any distinguishing features (so that – for instance – an unconscious person might be identified);

14.2. the name and address of general practitioner and whether they have a copy;

14.3. a statement that the document should be used if the maker lacks capacity to make treatment decisions;

14.4. a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;

14.5. the date the document was written (or reviewed); and

14.6. the person’s signature (or that of the person signing in their presence on their behalf) and the signature of a witness (if there is one).

15. These provisions of the Code of Practice have been the subject of specific judicial endorsement.17

16. As per the position previously, an advance decision can only stand as an advance refusal of treatment; a person cannot require that they be given a specific treatment: as Paragraph 9.5 of the MCA Code of Practice puts it “Nobody has the legal right to demand specific treatment, either at the time or in advance. So no-one can insist (either at the time or in advance) on being given treatments that healthcare professionals consider to be clinically unnecessary, futile or inappropriate.” That having been said, a request that healthcare professionals consider giving specific treatment(s) would undoubtedly stand as an expression of past wishes

17 By Theis J in X Primary Care Trust v XB [2012] EWHC 1390 (Fam) at paragraph 34.
to be taken into account in any decision being taken on a best interests basis under the provisions of s.4(6)(a) (and, if written down, would carry additional weight).

Capacity

17. There have been no cases reported since the passage of the MCA addressing in detail the components of the test for capacity to enter into an advance decision. However, the following points can be made:

17.1. the normal provisions of the Act relating to capacity (enshrined in ss.1-3) apply to the question of whether the person at the time of making the decision has the capacity to do so (including that the person should be presumed to have the capacity to take the decision). The “salient details” relevant to such a decision are, it seems to me, few in number, and can be reduced to the following:

17.1.1. the nature of the treatment(s) that is/are to be covered by the advance decision, including, if various forms of intervention are necessary to support a particular purpose, that there is more than one intervention, and the core elements of those forms of intervention which are to be covered;

17.1.2. the circumstances (if such are specified) under which the treatment(s) are not to be started or continued;

18 See CC v KK and STCC [2012] EWHC 2136 (COP) at paragraph 22 per Baker J: “... I bear in mind and adopt the important observations of Macur J in LBL v RYJ [2010] EWHC 2664 (Fam) (at paragraph 24), that ‘it is not necessary for the person to comprehend every detail of the issue ... it is not always necessary for a person to comprehend all peripheral detail ....’ At paragraph 58 of the judgment, Macur J identified the question as being whether the person under review can ‘comprehend and weigh the salient details relevant to the decision to be made’. A further point – to my mind of particular importance in the present case – was also made by Macur J at paragraph 24 in that judgment: ‘...it is recognised that different individuals may give different weight to different factors.’”

19 In this regard, I would suggest that – not least as there is no concept of ‘informed consent’ in the law of England and Wales, the understanding of the nature of this treatment would need to be no greater than would be required in order for the person to give their consent to it if it was being offered there and then.

20 In A Local Authority v E [2012] EWHC 1639 (COP), discussed further below, Peter Jackson J had cause to consider whether E had capacity to refuse force-feeding. This raised the further question, he found, as to whether she had the capacity to refuse other forms of treatment, such mechanical ventilation, which might be necessary to sustain her during forcible feeding. He held that it was “artificial to treat the various forms of intervention involved in forcible feeding individually. They are all central to or supportive of a single purpose. I therefore find that E lacks capacity to accept or refuse treatment in relation to any interventions that are necessary in conjunction with forcible feeding” (paragraph 67). This conclusion came in the context of a discussion as to whether E had had capacity to make an advance decision to refuse tube feeding or life support if she was close to death; it would appear that Peter Jackson J’s conclusions although framed as if referable only to the situation at the time of the hearing before him, were also intended to have retrospective effect.
17.1.3. the consequences of refusing the start or the continuation of that treatment (and, in the case of life-sustaining treatment, that such may result in death);

17.1.4. that the decision can be withdrawn or changed at any time whilst the person still has capacity to do so; but that

17.1.5. if the decision is not withdrawn or changed, and the person loses capacity to consent to the carrying out or continuation of treatment, that decision will bind the medical professionals and may do so even if – at the time – the individual is indicating that they do not wish it to;21

17.2. It is necessary for those considering the question of whether someone has capacity to make an advance decision to be careful to restrain any inclination to give into the ‘protection imperative’22 by setting the threshold too high. As part of this (and/or allied to this), it is necessary always to be alive to the fact that a person can refuse medical treatment on grounds that are entirely unrelated to that treatment and/or fundamentally unwise and/or deeply alien to all the instincts of a medical or social work professional.23 If they can refuse medical treatment now on such grounds, then respect for their autonomy means that they should be able to refuse it for the future on the same basis;

21 A point to which I return below.
22 See by analogy CC v KK and STCC [2012] EWHC 2136 (COP) at paragraph 25 (per Baker J): “There is a further point, to which I alluded in an earlier decision in PH v A Local Authority, Z Ltd and R [2011] EWHC 1704 (Fam). In assessing the evidence, the court must be aware of the difficulties which may arise as a result of the close professional relationship between the clinicians and professionals treating and working with, P. In PH, I drew attention to a potential risk, identified by Ryder J in Oldham MBC v GW and PW [2007] EWHC136 (Fam) [2007] 2 FLR 597, another case brought under Part IV of the Children Act 1989, that the professionals and the court may be unduly influenced by what Ryder J called the ‘child protection imperative’, meaning ‘the need to protect a vulnerable child’ that, for perfectly understandable reasons, may influence the thinking of professionals involved in caring for the child. Equally, in cases of vulnerable adults, there is a risk that all professionals involved with treating and helping that person – including, of course, a judge in the Court of Protection – may feel drawn towards an outcome that is more protective of the adult and thus, in certain circumstances, fail to carry out an assessment of capacity that is detached and objective. On the other hand, the court must be equally careful not to be influenced by sympathy for a person’s wholly understandable wish to return home.”
23 See, for instance, the dicta of Lord Donaldson MR in the (pre-MCA) case of Re T (Adult: Refusal of Treatment) [1993] Fam 95 at 115:

“Prima facie every adult has the right and capacity to decide whether or not he will accept medical treatment, even if a refusal may risk permanent injury to his health or even lead to premature death. Furthermore, it matters not whether the reasons for the refusal were rational or irrational, unknown or even non-existent. This is so notwithstanding the very strong public interest in preserving the life and health of all citizens. However the presumption of capacity to decide, which stems from the fact that the patient is an adult, is rebuttable.”

See also the views of the expert (Professor Sensky) endorsed by Butler-Sloss P in Re B (Adult: Refusal of Medical Treatment) [2002] 1 FLR 1090 at paragraph 78:

“one thing which struck him forcibly was that the clinicians started from the decision made by Ms B, and not from the assessment of her competence. They looked too much at the decision, which was contrary to their advice and which they would not endorse, and not enough at the surrounding circumstances. The clinicians were not able to accept her views and deal with them. It was a fundamental principle that one should start with the individual’s capacity to make decisions and values. There may have been some confusion over her values compared with other people’s, and it was important to focus on the individual and respect that individual’s values. The weight which an individual chooses to
17.3. allied to this, I note that there was some suggestion before the enactment of the MCA 2005 that it was a further pre-condition of an advance decision being made that the individual had had sufficient information on which to found a decision to refuse treatment. In the passage from AK cited above, for instance, Hughes J specifically directed himself that care had to be taken in deciding whether an advance decision was effective to investigate “with what knowledge the expression of wishes was made,” before going on to note that “[i]n the present case the expressions of AK’s decision are recent and are made not on any hypothetical basis but in the fullest possible knowledge of impending reality [AK suffering from motor neurone disease and indicating that he wanted artificial ventilation stopped two weeks after he could no longer communicate]. I am satisfied that they genuinely represent his considered wishes and should be treated as such. Whatever the precise position at common law, I would suggest that, save and to the extent that questions of information/knowledge relate to the treatment that the individual proposed to refuse (or the circumstances under which they propose to refuse it), and can properly be examined through the prism of ss.2 and 3 MCA 2005, they cannot enter the question of whether an advance decision has been made;

17.4. in this regard, I would further venture to suggest that it is irrelevant to the question of whether or not the person has capacity to make an advance decision to refuse life-sustaining treatment that they have a history of suicidal attempts or are expressing suicidal thoughts. It is only if those suicidal attempts/suicidal thoughts are manifestations of an impairment of or a disturbance in the functioning of the mind for purposes of s.2(1) and that impairment/disturbance gives rise to an inability to make the decision for purposes of s.3(1) that the attempts/thoughts become relevant;

give competing factors is an essential part of the decision-making process. A key issue in this case was the weighing up by Ms B of artificial ventilation and the stopping of ventilation and almost inevitable death. She valued the ventilator and her handicap as worse than being dead. Her decision was made against the advice offered and was not understood. Subjective values have to be taken into account. If at an earlier stage there had been an acknowledgement of a clash of values it might possibly have led to a different approach to management of the case.”


25 In the Australian context, in a case cited by Wilmott (op. cit.), McDougall J in the Superior Court of New South Wales in Hunger and New England Area Health Service v A [2009] NSWSC 761, held that he did not “accept the proposition that, in general, a competent adult’s clearly expressed advance refusal of specified medical procedures or treatment should be held to be ineffective simply because, at the time of statement of the refusal, the person was not given adequate information as to the benefits of the procedure or treatment (should the circumstances making its administration desirable arise) and the dangers consequent upon refusal. As I have said, a valid refusal may be based upon religious, social or moral grounds, or indeed on no apparent rational grounds, and is entitled to respect… regardless” (at paragraph 28).

26 The Code of Practice notes at Paragraph 9.9 that “[h]ealthcare professionals may have particular concerns about the capacity of someone with a history of suicide attempts or suicidal thoughts who has made an advance decision. It is important to remember that making an advance decision which, if followed, may result in death does not necessary mean that a person is or feels suicidal. Nor does it necessarily mean that the person lacks capacity to make the advance
17.5. where there are reasons for any healthcare (or indeed social work professionals) to consider that the person may lack the capacity to make the advance decision, a “full, reasoned and contemporaneous assessment to make such a momentous decision” should be undertaken and recorded so as to eliminate the possibility of later doubt: *A Local Authority v E*.27

18. The Act does not import – expressly – the concern expressed in pre-MCA 2005 cases as to identification of the circumstances under which the advance decision has been made, and in particular the concern to ensure that the advance decision was made without undue external influence.28 An interesting question as to the validity (or on a proper analysis, to the existence29 of an advance decision) would arise in circumstances where the person was capacitous within the meaning of the Act but was ‘vulnerable’ in the SA sense.30 I very strongly suspect that a Court would strive to find – by one route or another – that such an advance decision was not effective.31

decision. If the person is clearly suicidal, this may raise questions about their capacity to make an advance decision at the time they made it.” This seems to me rather to conflate the issues of whether the person had the capacity at the time that they made the decision and the question of how to establish that matter now. 27 [2012] EWHC 1639 (COP). In this case, discussed further below, Peter Jackson J held that on the facts of that case, such an assessment would in fact have been necessary against the particular “alerting background” which confronted healthcare professionals.

28 In this regard, see, in particular *Re T (Adult: Refusal of Treatment)* [1993] Fam 95, the dicta of Staughton LJ at 121 providing a useful summary of the position:

“The first reason [why it might be uncertain whether or not a competent adult does not or does not consent to the proposed treatment] is that the apparent consent or refusal was given as a result of undue influence. It is, I think, misleading to ask whether it was made of the patient's own free will, or even whether it was voluntary. Every decision is made of a person's free will, and is voluntary, unless it is effected by compulsion. Likewise, every decision is made as a result of some influence: a patient's decision to consent to an operation will normally be influenced by the surgeon's advice as to what will happen if the operation does not take place. In order for an apparent consent or refusal of consent to be less than a true consent or refusal, there must be such a degree of external influence as to persuade the patient to depart from her own wishes, to an extent that the law regards it as undue. I can suggest no more precise test than that. The cases on undue influence in the law of property and contract are not, in my opinion, applicable to the different context of consent to medical or surgical treatment. The wife who guarantees her husband's debts, or the widower who leaves all his property to his housekeeper, are not in the same situation as a patient faced with the need for medical treatment. There are many different ways of expressing the concept that what a person says may not be binding upon him; a Greek poet wrote 'my tongue has sworn, but no oath binds my mind.'"’

29 Existence being something upon which a Court can be asked to pronounce under s.26(4)(a). As discussed further below, ‘validity’ is something of a term of art for purposes of the MCA 2005, and would not seem to encompass considerations of the circumstances under which the decision was made.

30 “[i]n the context of the inherent jurisdiction I would treat as a vulnerable adult someone who, whether or not mentally incapacitated, and whether or not suffering from any mental illness or mental disorder, is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation, or who is deaf, blind or dumb, or who is substantially handicapped by illness, injury or congenital deformity. This, I emphasise, is not and is not intended to be a definition. It is descriptive, not definitive; indicative rather than prescriptive.” *Re SA (Vulnerable Adult with capacity: Marriage)* [2005] EWHC 2942 (Fam), [2006] 1 FLR 867, per Munby J. That the inherent jurisdiction survives in respect of this category of individuals is now beyond doubt: *DL v A Local Authority* [2012] EWCA Civ 253.

31 By analogy, in *XCC v AA & Ors* [2012] EWHC 2183 (COP), Parker J held that she had power under the inherent jurisdiction to grant relief in respect of an incapacitated adult where such relief was not available under the provisions of
19. So much for establishing capacity as at the point of making an advance decision. However, more than in almost any other aspect of the Court of Protection’s health and welfare jurisdiction, the Court will be concerned with retrospective assessment of the question of capacity. Some thoughts are therefore in order upon the question of the burden and standard and proof, because the law in this respect has evolved from that as set out in HE:

**Burden**

19.1. in HE, Munby J clearly placed the burden of proof upon those who seek to establish the existence and continuing validity and applicability of an advance directive. As a matter of necessary implication, this would include establishing that the person had the requisite capacity at the material time to create the advance decision;

19.2. reflecting the first principle of the Act, and as set down in the Code of Practice, the starting presumption should be that the person had the capacity to make an advance decision. Logically, therefore (and in 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;

19.3. however, it would seem that the Courts have (or may) sought to make an exception to this rule in the case of advance decisions (at least in the case of advance decisions to refuse life-sustaining treatment). In *A Local Authority v E*, decided earlier this year, Peter Jackson J had cause to consider two documents signed by E (a highly intelligent 32-year-old woman who suffering from extremely severe anorexia nervosa, and other chronic health conditions) saying that she did not want to be resuscitated or to be given any medical intervention to prolong her life. For present purposes, the significant facts and findings made in relation to those documents were as follows:

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32 A task which will always be rendered vastly less difficult if the suggestion in the Code of Practice (paragraph 9.8) is followed that healthcare professionals record their contemporary assessment of the person’s capacity to make an advance decision.
33 Section 2(2) “A person must be assumed to have capacity unless it is established that he lacks capacity.”
34 Paragraph 9.8.
35 *CC v KK and STCC* [2012] EWHC 2136 (COP) at paragraph 18; but see below for a nuance to this position which applies in one specific context.
19.3.1. E, whom Peter Jackson J found to have “thought a great deal about her medical treatment, with a view to preventing others feeding her,”\(^37\) first sought to make an advance decision in July 2011. At that point, at least one doctor believed that she had capacity (referring to the statutory test, but not providing any deeper analysis). Signed by E and countersigned by her mother, the document stated: “I do not want to be resuscitated or given any medical intervention to prolong my life.” Days later E was detained for treatment under s.3 MHA 1983 and PEG fed. Given the confusion amongst the medical, social work and legal professionals as to her capacity, together with her parents’ expressed doubts as to her true intentions at that time, Peter Jackson J decided that she lacked capacity to make a valid advance end of life decision;\(^38\)

19.3.2. over the next three months, “in the hope that she would achieve sufficient weight to be regarded as being capable of making another advance decision,”\(^39\) to maximise her chances of being found to have capacity, E reluctantly complied with the PEG feeding and her BMI peaked at 15 by October 2011. Having received legal advice, she signed another advance decision witnessed by her mother and an independent mental health advocate. It stated that, if close to death, she did not want tube feeding or life support but would accept pain relief and palliative care. It also read: “[i]f I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision.” That day, E was again detained for treatment under s.3 MHA 1983;

19.3.3. save in one respect (the attempt to dictate that subsequent behaviour should be ignored), Peter Jackson J found that this decision satisfied all of the formalities required by s.25 MCA 2005 (addressed further below). The critical question, therefore, was whether E had had capacity to make the October 2011 decision. As at that point, Peter Jackson J accepted:

“E and her mother had been given reason to believe that E had capacity. E had the benefit of advice from her independent mental health advocate and from a solicitor. This also appears to have been the general medical view, but no formal capacity assessment was undertaken at the time. Moreover, E was again placed under Mental Health Act section on the day the document was signed and on the next day she was received into the care of Professor L for assessment. In his report made on 17 October, Professor L does not specifically deal with the question of

\(^{37}\) Paragraph 19.

\(^{38}\) Paragraph 58. Peter Jackson J also found that “to an extent, this [conclusion] is confirmed by her subsequent attempt to put herself in a position to make an advance decision that would be accepted as valid” (paragraph 59).

\(^{39}\) Paragraph 60.
capacity, but his general approach can be deduced from the fact that he recommended treatment, despite recording E’s opposition very fully.”

19.3.4. from later passages in the judgment, it appears clear that that two doctors (Drs V and L) expressed to the Court the opinion that she had had the capacity at the material time; 40

19.4. the judgment does not record how the matter of how to resolve the question of E’s capacity as at October 2011 was put to Peter Jackson J. 41 He recorded the statutory presumption of capacity at an earlier stage in the judgment, 42 in his analysis of the question of E’s capacity in October 2011. At paragraph 55, he held 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.”

19.5. in line with this approach, he moved (having discussed the evidence) to a conclusion that:

“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.” 43

19.6. I would respectfully suggest that if and to the extent that Peter Jackson J was intending to suggest at paragraph 55 that (without more) the burden of proof is upon the maker (or those ‘supporting’ the maker) to establish capacity at the material time this cannot be correct;

19.7. at most, I would suggest that the position is akin to that which pertains in respect of cases where the capacity of an individual to make a lifetime gift is impugned, in which there is authority to suggest

40 See paragraphs 86 and 110. Dr D was E’s consultant psychiatrist at the time (paragraph 109).
41 I understand, in fact, that Peter Jackson J did not invite submissions on the approach to be adopted. E was represented at the hearing by the Official Solicitor, who did not (it appears) advance a case that she had had the capacity at the material time, although I note that Peter Jackson J recorded – in the context of a consideration of her current capacity to consent to or refuse medical treatment – the observation of Counsel instructed by the Official Solicitor that in the absence of contrary medical opinion he would have felt able to take instructions from E (paragraph 51). It is not altogether clear whether E’s parents – who appeared for themselves – advanced a positive case that their daughter had had capacity at the material time, their primary position being to “fight for her best interests which, at this time, we strongly feel should be the right to choose her own pathway, free from restraint and fear of enforced re-feed... We want her to be able to die with dignity in safe, warm surroundings with those that love her” (paragraph 80).
42 Paragraph 47.
43 Paragraph 65.
that once a prima facie case has been established that the person lacked the relevant capacity, then the evidential burden shifts to those person(s) seeking to establish that the relevant capacity was present.44

19.8. Peter Jackson J’s silence as to the approach that he was adopting to the question of the burden of proof leaves open another possibility, namely that he proceeded on the basis that as the Court has an inquisitorial rather than adversarial jurisdiction questions of burdens of proof do not arise.45 If he did so, then I would respectfully suggest that that would not be correct,46 as this would be to deprive a

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44 See Gorjat v Gorjat [2010] EWHC 1537(Ch) at paragraph 139 per Sarah Asplin QC (sitting as a Deputy High Court Judge):

“[f]inally, at common law, the burden of proving lack of mental capacity lies on the person alleging it. To put the matter another way, every adult is presumed to have mental capacity to make the full range of lifetime decisions until the reverse is proved. Section 1(2) Mental Capacity Act 2005 which came into force after the decision which is under consideration in this case, put the presumption of mental capacity on a statutory footing. This evidential burden may shift from a claimant to the defendant if a prima facie case of lack of capacity is established: Williams v Williams [2003] WTLR 1371 at 1383.”

In Williams v Williams (a pre-MCA case), Kevin Garnett QC (sitting as a Deputy High Court Judge) had discussed the matter thus:

“44. In relation to the burden of proof, Miss Angus, who appeared for John, submitted that a prima facie case of lack of capacity having been raised, the evidential burden of proof then shifted to George and Marion to satisfy the court that John in fact had capacity. In my judgment, this normally sterile kind of point has some significance in this case for two reasons. First, the evidence is that John would only have understood the nature of the transaction if he had had it carefully explained to him. Unless, on the balance of probabilities, he had such an explanation, the gift will fail. Who has the burden of establishing the point? Second, the evidence about what advice John actually received is, to put it no higher, unsatisfactory.

45. For what is worth, and despite the deprecation of resort to concepts of shifting burdens of proof in cases of the present kind by Sir Christopher Staughton in Re W [2001] Ch 601, I accept Miss Angus’ submission. It seems common sense and has the support of Rimer J. in The Special Trustees for Great Ormond Street Hospital for Children v. Rushin (19th April 2000, unreported). There, he had found that the donor was suffering from Alzheimer’s disease. He then said:

‘having found, as I have, that by 1996 [the donor] was suffering from a material degree of dementia occasioned by Alzheimer’s disease, I consider that the burden of proving that [she] had the requisite degree of capacity shifted to [the defendants].’”

45 Cf the approach taken by Baker J in Cheshire West and Chester v P [2011] COPLR Con Vol 273 to deprivation of liberty: “52. I unhesitatingly accept Mr O’Brien’s submission on this point and reject Mr Allen’s contention. The processes of the Court of Protection are essentially inquisitorial rather than adversarial. In other words, the ambit of the litigation is determined, not by the parties, but by the court, because the function of the court is not to determine in a disinterested way a dispute brought to it by the parties, but rather, to engage in a process of assessing whether an adult is lacking in capacity, and if so, making decisions about his welfare that are in his best interests. It may be that one party or another asserts a fact which, if in dispute, must be proved, to the requisite standards of the balance of probabilities, but the question of whether or not the circumstances as a whole amount to a deprivation of liberty is not one which fails to be determined by application of a burden or standard of proof.”

46 For different reasons, although I do not address it here as it is a tangent, I would also respectfully disagree with the conclusion of Baker J at paragraph 52 of Cheshire West (a point which was not appealed to the Court of Appeal), not least because it is difficult to square both with the conventional approach that victims of breaches of Convention rights fall
person of much of the benefit of the statutory presumption of capacity enshrined in statute. Requiring another person to advance a positive argument to the Court that P lacked the capacity at the material time (even if that is only to require them to raise a prima facie case to this end) seems to me an important safeguard which would be lost if the Court sought to determine the question without reference to burdens of proof.

Standard of proof

19.9. the position in relation to the standard of proof required has also evolved somewhat since that set down in HE. The reader will recall that in that case, Munby J held that “[w]here life is at stake the evidence must be scrutinised with especial care. Clear and convincing proof is required. The continuing validity and applicability of the advance directive must be clearly established by convincing and inherently reliable evidence.” In so doing, he relied (at paragraph 24) upon the dicta of the House of Lords in Re H (Minors) (Sexual Abuse: Standard of Proof) to support the proposition that “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.”

19.10. however, first the House of Lords and subsequently the Supreme Court has reaffirmed in clear terms that there is but one civil standard of proof and that questions of gravity do not give rise to additional requirements of cogency: see, most recently, Re S-B [2010] 1 AC 678.

19.11. in the first passage from E looked at above in relation to burden of proof, Peter Jackson J held that for “an advance decision relating to life-sustaining treatment to be valid and applicable, there should be

within the general rule that he who asserts must prove and with the dicta of the Lord Dyson in Lumba v Secretary of State for the Home Department [2011] 1 AC 245 as to the approaching to be taken to the establishment of false imprisonment, where he identified that “[a]ll that a claimant has to prove in order to establish false imprisonment is that he was directly and intentionally imprisoned by the defendant, whereupon the burden shifts to the defendant to show that there was lawful justification for doing so” (paragraph 53).


48 Entirely consistent with this, s.2(4) MCA 2005 provides that “[i]n proceedings under this Act or any other enactment, any question whether a person lacks capacity within the meaning of this Act must be decided on the balance of probabilities.”

49 See paragraph 11 (per Baroness Hale JSC, giving the judgment of the Court): “None of the parties in this case has invited the Supreme Court to depart from those observations [relating to In re B (Children) (Care Proceedings: Standard of Proof) (CAFCASS intervening) [2009] AC 11], nor have they supported the comment made in the Court of Appeal [2009] 3 FCR 663, para 14, that In re B ‘was a sweeping departure from the earlier authorities in the House of Lords in relation to child abuse, most obviously the case of In re H.’ All are agreed that In re B [2009] AC 11 reaffirmed the principles adopted in In re H [1996] AC 563 while rejecting the nostrum, ‘the more serious the allegation, the more cogent the evidence needed to prove it,’ which had become a commonplace but was a misinterpretation of what Lord Nicholls had in fact said.” (emphasis added).
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.  

19.12. To the extent that this statement represents no more than an identification of the fact that (putting aside questions of the burden) the Court needs to be able to be satisfied on the balance of probabilities that the maker of the advance decision had capacity at the time to make an important decision with far-reaching consequences, this is entirely unexceptionable. To the extent that it might be read as suggesting that particularly clear evidence is required because of the nature of the decision, I would again respectfully suggest that it is incorrect in adding a gloss upon the civil standard of proof that the Supreme Court has ruled out.

Validity

20. Consistent with the concern identified in the pre-MCA case-law to identify both the validity and the applicability of an advance decision, the Act sets out a series of requirements which must be satisfied before the person treating P is bound to honour it under the provisions of s.26(1) (discussed further below). In so doing, the MCA 2005 sharply distinguishes between ‘ordinary’ medical treatment and life-sustaining treatment in a way that was not the case at common law.

21. In both cases, for an advance decision to be valid, then by s.25(2) P must not have:

21.1. withdrawn the decision at a time when he had capacity to do so;

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50 Paragraph 55.
51 To take an analogous example from a recent case: see also Re D(Children), a decision of the Court of Appeal reported on Lawtel on 18.10.12 (relating to allegations that a 13-year old boy had raped his sister a number of times), where the Court of Appeal reaffirmed the position that: “whatever the allegations, and however serious they were, the simple balance of probabilities remained the standard of proof to be applied; findings should be made without regard to the gravity of the consequences.”
52 Or potentially incur liability for so doing. See further s. 25(1) (and ss.26(2)-(3), discussed below).
53 ‘Treatment’ including – by s.64(1) – diagnostic or other procedures.
54 Defined in s.4(10) as being treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.
55 Section 24(3) providing that P can withdraw or alter an advance decision at any time when he has capacity to do so; s.24(4) that such a withdrawal (including a partial withdrawal) need not be in writing; and s.24(5) that an alteration need not be in writing unless the decision resulting from the alteration brings it within the scope of the provisions of s.25(5) relating to life-sustaining treatment. There is an interesting question whether the threshold for capacity to withdraw an advance decision is lower or equivalent to the threshold for capacity to amend an advance decision (the threshold for capacity to amend an advance decision logically being the same as the threshold for capacity to make an advance decision). Instinct might suggest that it is lower, but I would suggest that it should be the same (not least because s.2(4)(c)) requires that one of the reasonably foreseeable consequences of the decision that must be understood is failing to make it at all).
21.2. by a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any one of them) to give or refuse consent to the treatment to which the advance decision relates;  

21.3. have done anything else clearly inconsistent with the advance decision remaining his fixed decision.

22. Note that this list is worded in exhaustive terms: these are the only grounds upon which an advance decision is not to be considered valid within the meaning of the Act. The word ‘valid’ therefore represents something of a term of art and does not – for instance – encompass considerations of whether the advance decision was properly made in the first instance. An advance decision which a person purports to make when they lack the capacity to do so is an advance decision which does not exist (as with an advance decision which is made by a person with the capacity to do so but under duress); an advance decision refusing life-sustaining treatment which does not comply with the formalities required by s.25(5) and (6) discussed further below is an advance decision which is not applicable (but well could still be ‘valid’ within the meaning of the Act).

23. The Act is silent as to questions of burden and standard of proof as regards evidencing the continuing validity of an advance decision. The approach set down in HE, discussed at length above, would suggest that the burden remains with the person asserting its validity. I would suggest that, for analogous reasons to those relating to the question of whether the individual had capacity to make the advance decision in the first place, the enactment of the MCA means that the burden should instead lie on the person who wishes to raise a doubt as to the continued validity of the decision, albeit that the burden may then shift if there is a prima facie case raised that one of the conditions set out in ss.25(2)(a)-(c) applies.

24. There is no requirement in the Act that an advance decision be renewed after a fixed period of time for it to be valid, such that an advance decision can in theory run indefinitely. Whilst it is undoubtedly sensible to keep advance decisions under review as the individual’s circumstances (not to mention the law and medical science) evolve, it is necessary to be very careful to ensure that they are not accidentally brought to an end thereby. In X Primary Care Trust v XB, what might have been thought to be a sensible attempt in a pro-forma advance decision to cater for regular reviews very nearly led to disaster. It therefore stands as a cautionary tale:

56 I discuss the alternative of creating a lasting power of attorney below in section D.
57 And hence the only grounds upon which an advance decision could be declared by the Court of Protection not to be valid under s.26(4)(b).
58 And hence that a decision may be superseded by events falling within s.26(4)(c).
59 [2012] EWHC 1390 (Fam).
24.1. XB, who suffered from Motor Neurone Disease, sought to make an advance decision that he wished life-sustaining treatment to be withdrawn as at the point when he was no longer able to communicate his needs or have control over his decisions as to his care and management. As he was unable to write (or indeed to communicate other than moving his eyes) at the material time, it was necessary for the advance decision to be completed on his behalf. The advance decision was recorded on a pro-forma downloaded from the internet. The form included a box to enter a date upon which it was to be reviewed; it also included a box to enter a date against the cryptic entry ‘valid until;’

24.2. doubt having arisen as to the circumstances under which XB had made the advance decision and in particular, as to whether he given his express consent by moving his eyes, the Primary Care Trust investigated and ultimately brought the matter before the Court of Protection. However, as it had taken over a month to investigate the circumstances, the matter did not come before the Court until days before the ‘valid until’ date upon the form. XB’s condition had progressed to the point where it appeared that he lacked the capacity to communicate (and hence, prima facie, the decision would potentially be applicable to the continuation of life-sustaining treatment). The Court was in receipt of expert evidence that XB did indeed lack the capacity to communicate his decision as to the continuation of life-saving treatment. The Court had to decide in very short order\(^{60}\) whether the advance decision was valid and (if so) whether the words ‘valid until’ in fact meant what on their face they did. Had they done so, and had the advance decision been valid, then XB – who was no longer in a position to make a fresh advance decision but was still conscious and alert – would have been in the position where; (1) his original decision would have expired and those near to him could no longer lawfully act upon it; (2) in light of the case-law upon withdrawal of life-sustaining treatment, his wishes as contained in the original decision would very likely not have been determinative of the question, and there would there therefore have been a very real prospect that the Court would have find that withdrawal was not in XB’s best interests; and (3) XB would have been aware that his wishes as contained in the decision were not being acted upon in precisely the circumstances in which he had sought them to be honoured;

24.3. fortuitously (if that is the correct word in such a situation), Theis J was able to find upon the facts before her that the date had been entered by one of the professionals attending XB at the point at which the advance decision had been made without discussing it with him and without XB’s consent,

\(^{60}\) The matter first came before the Court on a Friday; a two-day hearing was concluded by close of play on the Tuesday (the ‘valid until’ date being the Wednesday).
such that XB had not intended to time-limit his advance decision. Evidence having been received which allayed the earlier concerns as to the circumstances under which the decision had been made, Theis J was therefore able therefore to make a declaration that the advance decision was properly made and was not time-limited. Unsurprisingly, Theis J emphasised for the future that: (1) in the event that an issue is raised as to the circumstances in which an advance decision has been made, this should be investigated as a matter of urgency by the relevant statutory body; and (2) organisations producing pro forma documents might wish to look again at the merits of including a ‘valid until’ date.

25. The effect of s.25(2)(c) is that (consistent with the position that pertained at common law), an advance decision cannot contain a binding instruction to others to ignore behaviour that appears to contrary to the advance decision as such would be inconsistent with s.25(2). It would appear that a Court could simply strike out such a sentence (as both Munby J and Peter Jackson J seemed prepared to do in HE and E respectively), consistent with the – relative – lack of formality required in the actual wording of an advance decision. In other words, the presence of such an instruction would not suffice to vitiate the entirety of the advance decision.

26. The wording of s.25(2)(c) also throws up a two real questions, which have not yet been the subject of judicial determination (although they have been the subject of some brief judicial consideration):

26.1. is it apt to cover only actions carried out prior to the onset of incapacity, or can it also cover the position where a person no longer has capacity to alter or withdraw their advance decision (and as a corollary whether to accept or refuse medical treatment)? In other words, is it apt to cover the ‘twilight’ situation envisaged by Munby J in HE where a person still has the ability (to a greater or lesser extent) to express his wishes and feelings whilst not retaining the capacity to alter or revoke his advance decision;

26.2. further, what exactly does ‘do’ mean for purposes of s.25(2)(c). Does it require that a person has taken a positive action (such as, in HE’s case, convert to Islam and thereby abandon the central assumption upon which the decision was based), or can it extend to words alone?

27. I offer some tentative thoughts in respect of each of these questions:

See A Local Authority v E at paragraph 63, where Peter Jackson J (obiter) would have found invalid an instruction to the effect that “[i]f I exhibit behaviour seemingly contrary to this advanced directive this should not be viewed as a change of decision.”
27.1. on a narrow reading of s.25(2)(c), it could be said that it is only apt to cover actions taken up to the point where the person lost the capacity to withdraw the advance decision. It is, in other words, a sub-section which applies to the position where the person could have, but did not (for whatever reason) in fact withdraw the decision, not to the position where the person could no longer withdraw it and is therefore – prima facie – to be taken to be relying upon it as giving the answer to any question that a healthcare professional would have wished to pose them in respect of treatment to which they can no longer answer because they lack the capacity to consent to or refuse that treatment;

27.2. in support of this proposition, s.25(2)(c) talks of the things being done being clearly inconsistent with the advance decision remaining the person’s “fixed decision.” As a matter of logic, if one no longer has the capacity to withdraw a decision, one can no longer have the capacity to “unfix” that decision. Further, 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). Finally, keeping a bright line distinction between the position before and after the loss of capacity to withdraw an advance decision does provide a clear (if potentially clinically and ethically challenging) answer to the dilemma posed by Munby J in HE. If s.25(2)(c) only applies to things done before the loss of capacity, then manifestations of wishes and feelings thereafter cannot count. This draws a very clear distinction between the two ‘selves’ in play, and also places a particular burden on the self with capacity, knowing when they do that they are potentially binding medical teams to refuse treatment to their incapacitated self even when that latter self is begging for such treatment and/or (say) complying with other aspects of medical care;

27.3. whilst this narrow approach might be said to have been the subject of (obiter) endorsement in W v M, its implications are, however, sufficiently stark that I suspect that most clinicians (and judges) confronted with it would seek to find some way in which to avoid them whenever the person exhibits behaviour other than compliance. In E, Peter Jackson J (obiter) gave brief consideration to E’s actions and words in the period after she made the second of her two ‘advance decisions.’ Because he had already found that she did not have capacity to make either of them, he did not have to decide whether

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62 Again, noting here the question of whether the capacity required for these two is the same.
63 At paragraph 229, Baker J responded to a submission made by Counsel for W (M’s mother) that “if the possibility that an incapacitated adult had changed her mind after becoming incapacitated was ‘fatal to giving substantial weight to M’s previous or likely views ... then no advance decision could ever be upheld, on the basis that P could have changed his or her mind’. But the crucial distinction between an advance decision that meets the criteria required by sections 24 to 26 of the 2005 Act and other expressions of wishes and feelings is that an advance decision must address specifically the circumstances in which it will be binding and is made in the knowledge that it will be decisive if those circumstances arise. In other words, an adult who makes an advance decision knows that it will be decisive in the event that he or she becomes incapacitated and is unable to communicate their current wishes and feelings.”
she had done something clearly inconsistent with the second in time remaining her fixed decision (or at what point she might have lost capacity to withdraw that decision). His discussion (at paragraph 69), seems, though, to have proceeded on the basis that he would examine both E’s actions and certain statements advanced in support of the proposition that she had done something clearly inconsistent with her decision, without reference to the fact that they were done/made at a time when she did not have capacity to withdraw the advance decision;

27.4. the discussion in E also suggests that there may be a distinction between actions and words. Peter Jackson J noted that E’s behaviour – refusing food – had been entirely consistent with her decision; he also indicated that he “would have been reluctant to conclude that her decision was undermined by trusting statements about what are bound to be deeply mixed feelings.” This distinction is undoubtedly one that finds a place in the language of s.25(2)(c), as it is not the most obvious use of language to calling ‘saying’ something ‘doing’ something. However, I suspect, again, that a Court would strain to diminish such a distinction to the point of nothingness in a case where (unlike with E) the person in question is unable to ‘do’ anything but was rather confined to communication alone (whether in words or, as in the case of XB, by moving his eyes);

27.5. although as a matter of law still remains unresolved (perhaps surprisingly given the length of time since the passage of the Act), it seems to me that the reality is that any advance decision to refuse treatment (or at least life-sustaining treatment) will be viewed with very acute caution – and may well not be honoured – until:

27.1.1. the individual has lost capacity to withdraw the decision; and

27.1.2. they have lapsed into unconsciousness, an MCS or a PVS, or for some other reason are no longer in a position to communicate or indicate any form of wishes or feelings, whether verbally or otherwise; and/or

27.1.3. whether because of their inability to communicate or indicate any forms of wishes or feelings or because they remain compliant, there are no contrary indications (of any kind) to suggest that the advance decision should not be considered valid and potentially applicable.

Applicability

28. For any advance decision to be applicable to the treatment in question, then:
28.1. at the material time, P must lack the capacity to give or refuse consent to it (s.25(3));

28.2. the treatment must be the treatment specified in the advance decision (s.25(4)(a));

28.3. such circumstances as are specified in the advance decision must be present (s.25(4)(b));

28.4. there must not be reasonable grounds to believe that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them (s.25(4)(c)).

29. Where the treatment contemplated is one that is not life-sustaining, then (as before) no formality is required in order for it to be considered valid or (potentially) applicable. Indeed (although this emerges by implication, rather than expressly from the Act), the decision need not be in writing; the potential difficulties that that poses in terms of establishing its validity and applicability at a later date are addressed at paragraph 9.23 of the Code of Practice, where the suggestion is made that healthcare professionals should, wherever possible, record a verbal decision in a person’s healthcare record. That note should include details both of the decision, and also those present (and in what role they were present, and whether they heard it, took part in it or are just aware that it exists).

30. Where the treatment contemplated is life-sustaining then (in a break with the position at common law), it is necessary for it to be applicable that, in addition:

30.1. the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk (s.25(5)(a));

30.2. the decision must be in writing, signed by P or another person in P’s presence and by P’s direction (s.25(5)(b); s.26(a); and (b);

64 Section 25(4)(c) provides another alternative route by which the full rigour of the consequences of making an advance decision can be avoided, because it could potentially be argued that inconsistent (but incapacitated) expressions of wishes and feelings post the loss of capacity to withdraw an advance decision represented circumstances which did not exist at the time that that decision was made and which would have affected his decision had he anticipated them. In other words, had P known that his incapacitated self would feel differently about his advance decision, one might suggest that he might not have made the advance decision in the first place. However, this is an argument which comes perilously close to replacing P’s autonomy with paternalism.

65 Paragraph 9.10 of the Code of Practice confirms that such an advance decision can be verbal; s.24(4) addresses withdrawal of an advance decision.

66 As noted earlier in the Code of Practice (paragraph 9.17) such a record would be confidential.
30.3. the signature must be made or acknowledged by P in the presence of a witness, and the witness must sign or acknowledge his signature in P’s presence (s.25(5)(b); s.26(c) and (d)). The absence of such a witness will render invalid advance decision refusing life-sustaining treatment: *An NHS Trust v D.*

31. Whilst entirely understandable given the serious implications of refusing life-sustaining treatment, the effect of the introduction of the increased level of formality required for such advance refusals can be to introduce an additional hurdle which some can no longer meet. For instance, by the time that the MCA 2005 came into force, Ms M (whose plight was examined in such detail by Baker J) had been in a coma (to be precise, in an MCS) for something over 4 ½ years, having suffered extensive and irreparable brain damage as a result of viral encephalitis that struck her down in February 2003. Ms M had never made an advance decision; however, as at the time when she might have done, there was no requirement in the then-judge made law that such a decision be (1) written down; or (2) witnessed.

67 [2012] EWHC 885 (COP) at paragraph 16. It is not entirely clear from this decision whether Peter Jackson J was also of the view that the purported advance decision in that case failed to comply with the requirement of s.25(5)(a) that it contain a statement that it was to apply even if life was at risk. In that case, D had developed a swelling in his thyroid gland which it was thought might be malignant. He underwent an operation in May 2011 which at first appeared to have been successful but further tests showed that another operation was necessary. This was performed on 25th July 2011. Unfortunately, it was found that the cancer had spread. Following the operation there were complications and in the course of a further procedure D suffered a cardiac arrest as a result of which he suffered severe and irreparable brain damage. He was treated, including with artificial nutrition and hydration, and for a time he required artificial ventilation. In advance of the surgery in July 2011, which “frightened him very much” (paragraph 15), D gave his sister-in-law, G, a signed letter reading thus:

“To whom it may concern: I authorise [and then G’s name and address] to act on my behalf in the event of me being unable to make decisions for whatever reason. In particular, I authorise the above to liaise with the medical profession in making decisions regarding any further medical treatment. More specifically, I refuse any medical treatment of an invasive nature (including but not restrictive to placing a feeding tube in my stomach) if said procedure is only for the purpose of extending a reduced quality of life. By reduced quality of life, I mean one where my life would be one of a significantly reduced quality, with little or no hope of any meaningful recovery, where I would be in a nursing home/care home with little or no independence. Similarly, I would not want to be resuscitated if only to lead to a significantly reduced quality of life.”

Whilst I do not understand that the point was the subject of any argument before Peter Jackson J because all concerned proceeded on the basis that the absence of a witness meant that the statement could not amount to an advance decision, for my part, it seems to me that it would be arguable that the last sentence would come close to the necessary verification that it was to apply even if life was at risk, because by definition resuscitation would only be considered by a medical team in such circumstances. However, it would undoubtedly be prudent to ensure that any advance decision being drafted ab initio contained such an express statement so as to avoid unnecessary doubts.

68 At paragraph 230, Baker J accepted “without qualification” the evidence of M’s sister and partner as to statements made by M in the past, and hence “that when her grandmother and father were in declining health and moved to live in nursing homes, M said on more than one occasion words to the effect that she would not wish to live like that, that she would not wish to be dependent on others, and that she “wanted to go quickly”. I also accept the evidence that, when reports about Tony Bland appeared on television, M expressed views to the effect that it would be better to allow him to die.” It was, however, common ground that there was no evidence that M ever specifically considered the question of withdrawal of ANH, or ever considered the question whether she would wish such treatment to be withdrawn if in a minimally conscious state.
32. Not in all such cases will the fact that the person in question has at all points subsequent to 1 October 2007 been unable to make an advance decision give rise to such apparently harsh consequences: by virtue of Article 5 of the Mental Capacity Act 2005 (Transitional and Consequential Provisions) Order 2007/1898, where an adult has at all points subsequent to 1 October 2007 lacked the capacity to make a new advance decision, an advance decision can still apply to life-sustaining treatment even if it is not witnessed and does not contain the express statement that it is to apply to such treatment. However, it must still be written down.

33. Furthermore, there is undoubtedly a route by which a Court could give effect to a sufficiently precise advance refusal of life-sustaining treatment which did not comply with the strict formalities of s.25. As discussed in W v M, there could exist such a route through the operation of s.4(6) MCA 2005 and the requirement contained in s.4(6)(a) to take into account “the person’s past... wishes (and in particular, any relevant written statement made by him when he had capacity);” in other words, whilst the ‘advance decision’ would not be binding qua advance decision, it could be a factor of ‘magnetic importance’ in the balance sheet determination of the person’s best interests.69 Whilst I note that Peter Jackson J in D indicated a potential sympathy with this approach,70 if it became necessary to decide the point in a particular case the Court would most likely be met with vigorous representations from the Official Solicitor71 to the effect that such an approach would be inconsistent with the clear and precise terms of the Act; I also suspect that the most likely outcome would be akin to that in E,72 where Peter Jackson J was ultimately swayed by the presumption in favour of the preservation of life.73 It would, though, be a particularly acute dilemma for the Court in the event that it was confronted with detailed oral evidence74 of a pre-MCA 2005 advance refusal of life-

69 To use the language of Munby J (as he then was) in Re M [2011] 1 WLR 344 at paragraph 32 (and, before him, of Thorpe LJ).
70 Having set out the provisions of ss.25(5) and (6), he noted as follows: “I recite that series of requirements, which proved of no assistance to D, in case it should make the requirements better understood for the benefit of others. Nevertheless, had there been anything to put in the balance against the other evidence, D’s wishes would have carried very great weight with me. He was a very private man before his incapacity, who would have been horrified at the prospect of being kept alive in this condition, with the total loss of privacy that his dependency entails” (emphasis added). In D’s case, where D was in a PVS, Peter Jackson J could proceed on a ‘conventional’ best interests analysis to declare that withdrawal of life-sustaining treatment was in his best interests because all the evidence pointed one way. He did note at the conclusion that the withdrawal of treatment was in D’s best interests “and it is what he would want” (emphasis added).
71 As made in W v M.
72 Where, of course, the relevant ‘advance decision’ was made at a point when E lacked capacity, albeit that Peter Jackson J found that both E and her family had been given reason to consider that she had capacity, and her views were entitled to “high respect. She is not a child or a very young adult, but an intelligent and articulate woman, and the weight to be given to her view of her life is correspondingly greater” (paragraph 132).
73 Paragraph 140: “The competing factors [in the best interests balance sheet] are, in my judgment, almost exactly in equilibrium, but having considered them as carefully as I am able, I find that the balance tips slowly but inexorably in the direction of life-preserving treatment. In the end, the presumption in favour of the preservation of life is not displaced.”
74 For instance in the form of contemporaneous entries in the individual’s medical records.
sustaining treatment which was not written down and where the person had lacked the capacity to make a further advance decision at all points subsequent to the enactment of the Act.

The effect of an advance decision

34. By s.26(1) MCA 2005, a valid and applicable advance decision has effect as if the person has made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or not. By s.26(2), a person does not incur liability for carrying out or continuing treatment unless, at the time, they are satisfied that an advance decision exists which is valid and applicable to the treatment and continues to provide treatment. Conversely, by s.26(3), a person does not incur liability for the consequences of withholding or withdrawing treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment. The following points arise from these important provisions:

34.1. it must always be remembered that not all advance refusals of treatment are determinative:

34.1.1. where a person can be administered treatment under the provisions of s.58A MHA 1983 without their consent but with a second opinion, then an advance decision refusing treatment cannot prevent such treatment;

34.1.2. an advance decision can prevent treatment under the MHA 1983 which either: (a) requires consent and a second opinion (i.e. the very serious medical treatments falling under s.57 MHA 1983)75; or (b) attracts the additional protections required by s.58A MHA 1983, namely (at present) ECT and associated medicines;76

34.1.3. however, a valid and applicable advance decision refusing ECT could be overridden in an emergency if such (a) was immediately necessary to save the patient’s life; or (b) (not being irreversible) was immediately necessary to prevent a serious deterioration in their condition;77

75 Although, in reality, such treatment could never be administered to a patient without the capacity to consent to it: see paragraph 15.1 of the Code of Practice to the MCA 2005.
76 Other treatments can be specified by regulations. Section 58A(5)(e)(i) 1983 has the effect that the relevant clinician cannot certify that it is appropriate for the treatment to be given to a patient incapable of understanding the nature, purpose and likely effects of the treatment if it would conflict with “an advance decision which the registered medical practitioner concerned is satisfied is valid and applicable.” Section 58A(9)(a) and (b) ties the definitions of “advance decision” and “valid and applicable” to the MCA 2005.
77 See s.62(1)(a)-(b) read together with s.62(1A) MHA 1983. The provisions of s.62 also apply to treatments under s.57 although as Richard Jones points out in his Mental Health Act Manual (15th Edition, Sweet & Maxwell, 2012) at paragraph
34.2. the precise form of liability which would attach to a person for treating in the face of a valid and applicable advance decision is not spelled out in the Act. Although the question has not been the subject of judicial determination, given the terms of s.25(1), criminal liability could undoubtedly attach because the effect of s.25(1) is to deem there to have been a contemporaneous refusal of consent;\(^\text{78}\) tortious liability for trespass could also attach. Depending upon the context and whether the treating body was a public authority, an action could also lie under the HRA 1998 for a breach of Article 8 ECHR;

34.3. the Code of Practice suggests that having ‘genuine doubts’ about the existence, validity or applicability of an advance decision equates to not being ‘satisfied’ for purposes of continuing to provide treatment under s.26(2);\(^\text{79}\) for my part, I would have said that such doubts could only be said to be genuine if the healthcare professionals involved had taken steps (and could document having taken steps) to investigate prima facie concerns.

Engaging the assistance of the Court

35. If there is any doubt or disagreement over whether an advance decision exists, is valid or is applicable to a treatment, an application can be made to the Court of Protection for it to make declarations under the provisions of ss.26(4)(a)-(c) respectively.

36. Whilst a decision is being sought, those treating the person concerned are entitled to take nothing in the apparent advance decision as preventing them providing life-sustaining treatment or doing any act they reasonably believe to be necessary to prevent a serious deterioration in that person’s condition (s.26(5)).

37. The importance of bringing matters relating to the existence, validity and/or applicability of an advance decision to Court as quickly as possible was emphasised in the cases of \textit{A Local Authority v E} and \textit{X Primary Care Trust v XB}:

37.1. in the former, Peter Jackson J noted:
“E’s case should have been brought before the court long before it was. Her condition has been seen by those treating her as raising an ethical predicament since at least 2009, if not before. As long ago as July 2011, the health authority considered referring the matter to the court in the context of doubts over the validity of E’s advance decision. Apart from anything else, an earlier application might have allowed E herself to participate directly in the proceedings if she chose; as it was, her condition at the time of this hearing meant that this was not possible. It has also meant that the question of treatment has only been brought forward several weeks after E embarked down the palliative care pathway.”

“Where there is a genuine doubt or disagreement about the validity of an advance decision, the Court of Protection can make a decision: MCA Code of Practice at 9.67. If ever there was a case where this route might have been taken, this was it.”

37.2. in the latter, Theis J noted:

“Firstly, in the event that there is an issue raised about an advance decision, it is important it is investigated by the relevant health authorities or relevant bodies as a matter of urgency. This will clarify issues at an early stage. It will enable relevant primary evidence to be gathered (for example, by taking statements) and, if required, an application made to this court. The judges who sit in the Court of Protection are experienced in dealing with urgent applications, as this case has demonstrated.”

D: The alternative of a lasting power of attorney

38. For those advising upon the making of an advance decision, it is always vitally important to bear in mind that there is an alternative to such a decision which has the power to avoid at least some of the difficult pitfalls outlined above. A lasting power of attorney can be created with authority for the person chosen as donee to take health care decisions, including as to the refusal of life-sustaining treatment. Such authority must be expressly included in the instrument and is subject to any conditions or restrictions in the instrument.

39. Once registered, an appropriately worded LPA will put the donee in the shoes of the donor in respect of treatment decisions the donor no longer has the capacity to take, subject to two important caveats:

80 Paragraph 40.
81 Paragraph 54.
82 Or more than one.
83 Section 11(8)(a). The prescribed form of health and welfare LPA includes an option to give such authority (which must be specifically signed in the presence of a witness). The option provides: “I want to give my attorneys authority to give or refuse consent to life-sustaining treatment on my behalf.” It does not, interestingly, include the equivalent requirement to s.25(5) that the donor is aware that the authority is to apply even if life is at risk.
84 Section 11(8)(b).
85 A pre-condition to creation of an LPA: s.9(2)(b).
86 Section 11(7)(a) makes clear that an LPA authorising an donee to make decisions about personal welfare does not extend to making such decisions in circumstances where P lacks, or the donee reasonably believes that P lacks, capacity.
39.1. where P has lost capacity to revoke an LPA, an LPA can be revoked by the Court of Protection if the Court is satisfied that: (1) the donee has behaved, or are behaving, in a way that contravenes their authority or is not in P’s best interests; or (2) the donee proposes to behave in a way which in a way that would contravene their authority or is not in P's best interests.\(^87\)

39.2. the Court can also give directions with respect to decisions which the donee of an LPA has authority to make and which P lacks the capacity to make.\(^88\)

40. The powers of the Court under ss.22/3 MCA 2005 in the context of medical treatment have not been tested, so far as I am aware. The only case of which I am aware in which ss.22/3 have been the subject of judicial consideration arose in a rather different context,\(^89\) but the dicta of HHJ Marshall QC do provide some limited insight into the approach of the Court. At paragraph 11, she held:

“In my judgment, the key to giving proper effect to the distinction between an attorney’s behaviour as attorney and his behaviour in any other capacity lies in considering the matter in stages. First, one must identify the allegedly offending behaviour or prospective behaviour. Second, one looks at all the circumstances and context and decides whether, taking everything into account, it really does amount to behaviour which is not in P’s best interests, or can fairly be characterised as such. Finally, one must decide whether, taking everything into account including the fact that it is behaviour in some other capacity, it also gives good reason to take the very serious step of revoking the LPA.

At paragraph 13, noting the Court’s powers with regard to directing an attorney under s.23:

“... on a proper construction of s 22(3), the Court can consider any past behaviour or apparent prospective behaviour by the attorney, but that, depending on the circumstances and apparent gravity of any offending behaviour found, it can then take whatever steps it regards as appropriate in P’s best interests (this only arises if P lacks capacity), to deal with the situation, whether by revoking the power or by taking some other course.”\(^90\)

41. Both ss.22 and 23 therefore provide theoretical routes by which the Court could embark upon a best interests analysis of a refusal of life-sustaining treatment by a donee on the behalf of a donor. In any such analysis, however, the fact that the donor has given the donee express authority to refuse consent to life-sustaining treatment should (if not determinative) be a factor of very great weight. A possible example of where the Court might seek to take an alternative course would be where the donor had undergone a religious

\(^87\) Sections 22(3)(b)(i) and (ii), read together with s.22(4)(b).

\(^88\) Section 23(2)(a).

\(^89\) Re J (unreported, 6 December 2010). See the report on the 39 Essex Street COP Cases database: http://www.39essex.com/court_of_protection/browse.php?id=2910. The context was a debate whether the conduct of a donee other than in his capacity as donee could be relevant.

\(^90\) To similar end, see also Re Harcourt; The Public Guardian v A, a decision of Senior Judge Lush of 31.7.12.
conversion giving rise to a fundamentally different approach to questions of life-sustaining treatment, had not revoked the authority of the donee to refuse such treatment, and the donee then sought to exercise that authority.

42. For the sake of completeness, I note that a deputy does not stand in the same position as the donee of an LPA; depending on the terms of their appointment by the Court they can make healthcare decisions, but they can never refuse consent to the carrying out or continuation of life-sustaining treatment in relation to P.91

E: Conclusion

43. The relative paucity of reported cases upon advance decisions since the enactment of the MCA 2005 may potentially reflect the relative paucity of advance decisions that are in circulation;92 conversely, it may also reflect the extent to which the relationships between doctors, patients and family members at the point of treatment decisions are not ones that lend themselves to ready resort to the Court. From this tour d’horizon of the position some 5 years after the Act was enacted, though, it can be seen that one consequence of the lack of decisions is that a number of significant questions remain unresolved, both as to the precise extent to which the Act has modified the principles derived from common law, and as to the extent to which the approach adopted by the Courts to date is in fact compatible with the principles of the Act.

ALEXANDER RUCK KEENE
39 Essex Street
London
WC2R 3AT
alex.ruckkeene@39essex.com
www.copcasesonline.com
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91 Section 20(5).
92 Albeit by no means a statistically significant poll, it is perhaps noteworthy that, at a 39 Essex Street seminar given in the aftermath of W v M to an audience (predominantly) of lawyers interested in the field of medical treatment, only one audience member – me – had sought to make an advance decision refusing life-sustaining treatment (and I had only done so in light of my work upon that case).