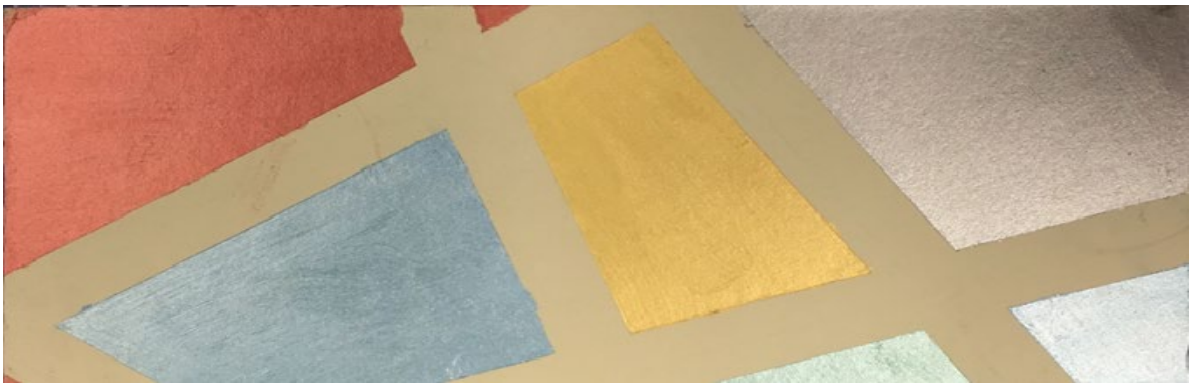

## A: Introduction

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.[1]

2. This paper examines the statutory framework. It is an updated version of a paper first written in December 2012, and then updated in June 2020. To the extent that anything in it is inconsistent with those earlier versions, this version should be taken as superseding them.

## B: Introduction

3. Advance decisions were first developed in the context of the common law, two key cases being *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129 and *HE v A Hospital NHS Trust* [2003] 2 FLR 408. The common law has now been "*refined*"[1] 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 proposed that they should continue to be governed by the common law. 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.

[1] For a clear statement of the importance of this, see *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26. Hyperlinks are to case summaries on the 39 Essex Chambers website or, in some cases, to the original judgment.

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The picture at the top, "*Colourful*," is by Geoffrey Files, an autistic man. I am very grateful to him and his family for permission to use his artwork.

4. I will analyse ss.24-6 in some detail, and in light of the glosses put upon it by case-law. I will proceed in stages, thus:

   4.1. the definition of an advance decision;

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

   4.3. conditions for validity;

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

   4.5. the effect of an advance decision;

   4.6. doubt and seeking the assistance of the court.

5. I then set out some thoughts about practical matters, including the alternative of appointing a lasting power of attorney.

## C: Definition of an advance decision

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

> *a decision made by a person ('P') after he has reached 18 and when he has capacity to do so, that if –*
>
> *(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and*
>
> *(b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment,*
>
> *the specified treatment is not to be carried out or continued.*

6. 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:[2]

   6.1. 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);

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

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

[2] Note that the Code is under review at the time of writing.

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

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

6.6. 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).

7. These provisions of the Code of Practice have been the subject of specific judicial endorsement.[3]

8. 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.*"[4] That having been said, a request that healthcare professionals consider giving specific treatment(s) would undoubtedly stand as an expression of past wishes 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).

## D: Capacity

9. Oddly, perhaps, the question of whether a person has capacity to make an advance decision does not go to the question of whether it is valid (this has a different, statutory, meaning, to which I return below). Rather, the easiest way of thinking about capacity is that, if the person does not have capacity to make an advance decision, they have not in fact created one at all – in other words, it goes to the **existence**[5] of the advance decision in the first place.

10. Surprisingly, 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:

10.1. The "*salient details*"[6] relevant to such a decision are, it seems to me, few in number, and can be reduced to the following:

[3] By Theis J in *X Primary Care Trust v XB* [2012] EWHC 1390 (Fam) at paragraph 34.
[4] See also *Aintree v James* [2013] UKSC 67 at paragraph 18.
[5] 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.
[6] 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.'*"

10.1.1. the nature of the treatment(s) that is/are to be covered by the advance decision,[7] 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;[8]

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

10.1.3. 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);

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

10.1.5. 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 potentially do so even if – at the time – the individual is indicating that they do not wish it to;[9]

10.2. It is necessary for those considering the question of whether someone currently has capacity to make an advance decision to be careful to restrain any inclination to give into the 'protection imperative[10]' 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

[7] In this regard, I would suggest that 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.
[8] 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.
[9] A point to which I return below.
[10] 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.*"

deeply alien to all the instincts of a medical or social work professional.[11] 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;

10.3. 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.[12] In *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129, 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;[13]

10.4. 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;[14]

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[11] See *Kings College Hospital NHS Foundation Trust v C & Anor* [2015] EWCOP 80

[12] See in this regard the interesting discussion of this train of judicial thinking in L Wilmott, *Advance Directives Refusing Treatment as an Expression of Autonomy: Do the Courts Practise What They Preach?* (2009) 38(4) Common Law World Review 295.

[13] 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).

[14] 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 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.

10.5. 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*.[15] I return to this at the end.

11. 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.[16] An interesting question as to whether an advance decision exists[17] would arise in circumstances where the person was capacitous within the meaning of the Act but was 'vulnerable' in the *SA* sense.[18] I very strongly suspect that a court would strive to find – by one route or another – that such an advance decision was not effective.

12. 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 is likely to be concerned with retrospective assessment of the question of capacity.[19] Some

[15] [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.

[16] 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] i*s 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*.'"

[17] Existence being something upon which the Court of Protection 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.

[18] "[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. For more on the inherent jurisdiction, see the 39 Essex Chambers Guidance Note here.

[19] 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.

thoughts are therefore in order upon the question of the burden and standard and proof in terms of establishing whether the person **had** had capacity to make an advance decision.

### Burden of proof

13. As the current iteration of the Code of Practice makes clear,[20] the starting presumption should be that the person had the capacity to make an advance decision.

14. However, this is not the end of the matter. Strictly, the presumption of capacity in s.1(2) MCA 2005 applies only to the current assessment of capacity, as it is clearly framed in the present tense: "[a] person must be assumed to have capacity unless it is established that he **lacks** capacity" (emphasis added). The MCA 2005 is silent as to the approach that is required to take in respect of the past assessment of capacity, even in those sections where it specifically empowers the Court of Protection to consider questions of the past capacity of the person ('P'), including (as we will see later) s.26(4)(a) (empowering the Court of Protection) to declare whether an advance decision regarding medical treatment exists).

15. There are undoubtedly sound reasons, not least so as to secure proper respect for P's rights under Article 8 ECHR, for the court to proceed in any retrospective assessment of P's capacity *as if* it were bound by the presumption in s.2(1). However, that still leaves room in an appropriate case for the court to proceed differently so as to secure P's interests. Advance decisions provide exactly such a case. This was identified, although without detailed analysis, by Peter Jackson J in *A Local Authority v E*.[21] The case concerned 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. One of the documents was an advance decision which, if it existed, would undoubtedly have been valid and applicable to the situation in which E found herself, and would have meant that she could not have been force-fed. Peter Jackson J held at paragraph 55 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*** (emphasis added)

16. Whilst Peter Jackson J's observations related to life-sustaining treatment, I would suggest that they apply to all forms of advance decisions to refuse treatment, and appropriately reflect the fact that the mechanical operation of the presumption in such a case could mean that medical practitioners would be **required** to abide by the advance decision notwithstanding the presence of such doubt. That would be a problematic outcome, not least in terms of the state's obligations to secure life under Article 2 ECHR.

[20] Paragraph 9.8.
[21] [2012] EWHC 1639 (COP).

17. The proper approach, in other words, is akin to the position (at common law) in relation to testamentary capacity or lifetime gifts. In such a case, if proper doubts have been raised (or, in legalese, 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.[22] Importantly, however, these considerations only arise if proper doubts have been raised as to the person's capacity at the point they purportedly made the advance decision. They are not a licence to unpick an advance decision which makes professionals (or family members) uncomfortable on the basis of spurious doubts.

### Standard of proof

18. Before the coming into force of the MCA 2005, Munby J had held in *HE* 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)*[23] 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.*" 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[24] and that questions of gravity do not give rise to additional requirements of cogency: see, for instance, *Re S-B* [2010] 1 AC 678.[25]

19. Especially in the context of life-sustaining treatment, the court will obviously scrutinise the evidence before it as to capacity anxiously. But it should also do so on the basis that the standard remains the civil standard of the balance of probabilities.

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[22] See, e.g.,*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 t 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.*" See also here the discussion of the retrospective assessment of capacity under the MCA 2005 in the Law Commission's 2025 Wills report at paragraphs 2.113 and 2.114.

[23][1996] AC 563.

[24] 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*." Strictly, however, this may not apply to retrospective assessments because the question is not whether the person **currently** lacks capacity, but whether they **lacked** capacity at the time they purportedly made the advance decision.

25 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).

## E: 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).[26] In so doing, the MCA 2005 sharply distinguishes between 'ordinary' medical treatment[27] and life-sustaining treatment[28] in a way that was not the case at common law. The importance of compliance with these provisions was emphasised by the then-Vice-President of the Court of Protection, Hayden J. in *NHS Cumbria CCG v Rushton*[29] thus (at paragraph 25):

> *Manifestly, these are documents of the utmost importance; the statute and the codes provide essential safeguards. They are intending to strike a balance between giving proper respect and recognition to the autonomy of a competent adult and identifying the risk that a person might find himself locked into an advance refusal which he or she might wish to resile from but can no longer do so. The balance is pivoted on the emphasis, in the case of life-sustaining treatment, given to compliance with the form specified by statute and codes.*

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;[30]

    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;[31] or

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

22. Note that this 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.[32] 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. As noted

[26] Or potentially incur liability for so doing. See further s. 25(1) (and ss.26(2)-(3), discussed below).
[27] 'Treatment' including – by s.64(1) – diagnostic or other procedures.
[28] 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.
[29] [2018] EWCOP 41. See also *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26.
[30] 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).
[31] I discuss the alternative of creating a lasting power of attorney below in section D.
[32] 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)

above, 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. 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 burden 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,[33] 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*,[34] 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:

    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[35] whether the advance

[33] And hence that a decision may be superseded by events falling within s.26(4)(c).
[34] [2012] EWHC 1390 (Fam).
[35] 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).

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, 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).[36] 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 two real questions:

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;

[36] 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*."

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. 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.[37] 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.

28. 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 applied to things done before the loss of capacity, then manifestations of wishes and feelings thereafter could not count. This would draw a very clear distinction between the two 'selves' in play, and also places a particular burden on the self with capacity, as that self would potentially ne 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.

29. However, the Court of Protection has taken a somewhat different approach. As regards the question of timing:

29.1. In *Re QQ*[38] Keehan J gave some passing (obiter) consideration to the meaning of the provision. It was obiter because he accepted that the person in question, QQ, had at all material times lacked the capacity to make decisions in relation to the specific medication under consideration. "*It follows*" [he held at paragraph 4] "*that I do not accept that when QQ made an advance decision in August 2015 in relation to her treatment that she was capacitous and therefore that it is a valid or lawful advance decision."* However, he continued, "[f]*f I were to be wrong on that issue, I accept Mr Wenban-Smith's submission that the contrary views that QQ has recently and fleetingly expressed from time to time, namely that she would accept treatment, would not of themselves invalidate, pursuant to s 25 (2) (c) of the Mental Capacity Act 2005, what would otherwise have been a valid advance decision*."

29.2. In *Re PW*,[39] Poole J set out his reasoning in more detail in a case in which he was required to consider whether post-incapacity actions could invalidate the apparent advance decision, and interpreted:

> *s.25(2)(c) as allowing for the advance decision to be rendered not valid should the person who made the advance decision do "anything else" (other than withdrawal or*

[37] Again, noting here the question of whether the capacity required for these two is the same.
[38] [2016] EWCOP 22.
[39] [2021] EWCOP 52.

> *granting an LPA which displaces the advance decision) which is "clearly inconsistent" with the advance decision remaining their fixed decision, before or after they have lost capacity to make the relevant treatment in question. The question will only arise after they have lost capacity but the court may consider things done before or after that time. Munby J refers to a person being locked into their advance decision once they have lost both capacity to decide whether or not to accept medical treatment and any ability to express their wishes and feelings. Similarly, s.25(2)(c) allows for a person who has lost capacity nevertheless to do something or to have done something which renders the advance decision not valid.* (emphasis added)

30. I note also that the Law Commission in its discussion of the potential for placing advance consent to what would otherwise be a deprivation of liberty on a statutory footing made clear that such should not apply where "*a person is subject to a confinement to which they do not have the capacity to consent, and to which their advance consent would on its face apply, but where their actions provide a clear indication that that advance consent should not be relied upon*." In so doing, the Law Commission expressly considered that this mirrored the approach under s.25(2)(c).[40]

31. In *PW*, Poole J also made clear that he considered that the word 'done' in s.25(2)(c) to include include words as well as actions, noting (at paragraph 52) that he was:

> *strongly reinforced in this view by what Munby said at paragraph [43] of his judgment in HE v A Hospital NHS Trust (above):*
>
> > *"No doubt there is a practical - what lawyers would call an evidential - burden on those who assert that an undisputed advance directive is for some reason no longer operative, a burden requiring them to point to something indicating that this is or may be so. It may be words said to have been written or spoken by the patient. It may be the patient's actions - for sometimes actions speak louder than words. It may be some change in circumstances. Thus it may be alleged that the patient no longer professes the faith which underlay the advance directive."*
>
> *The statutory provision does not refer to words and actions, only what P has "done", but it would be an odd restriction on the interpretation of "done" to exclude written or spoken words when the provision is addressed to previous written or spoken words in the form of an advance decision (an advance decision about treatment which is not life-sustaining treatment may be made verbally).*

32. In the same paragraph, Poole J also emphasised two other words in s.25(2)(c):

> *b. "clearly": the court should not strain to find something done which is inconsistent with the advance decision remaining the individual's fixed decision. Something done or said which could arguably be "inconsistent", or which the court could only find might be inconsistent will not suffice.*
>
> *c. "fixed": s.25(2)(c) does not merely require something done which is inconsistent with the advance decision, but rather something done which is inconsistent with it remaining the person's fixed decision. Fluctuating adherence to the advance decision may well be*

[40] Law Commission, Mental Capacity and Deprivation of Liberty, Law Com No 372 at paragraph 15.13.

*inconsistent with it remaining their fixed decision. As with the other elements of the test, whether it is inconsistent will depend on the facts of each case.*

33. I note, finally, that in *Briggs v Briggs (No 2)*,[41] Charles J noted (in relation to s. 25(2)(c) and s. 25(3)) that if following those provisions led the court to conclude that *"an advance decision was invalid or inapplicable, and so a best interests test became determinative, I consider that the court would have to take into account the impact of that removal of that person's right of self-determination that he or she has sought to exercise by making an advance decision."*[42]

## F: Applicability

34. For any advance decision to be applicable to the treatment in question, then:

    34.1. at the material time, P must lack the capacity to give or refuse consent to it (s.25(3));

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

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

    34.4. 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)).[43]

35. 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[44]), 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).[45]

36. Where the treatment contemplated is life-sustaining it is necessary for it to be applicable that, in addition, that the following are complied with:

[41] [2016] EWCOP 53.
[42] At paragraph 22.
[43] 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.
[44] 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.
[45] As noted earlier in the Code of Practice (paragraph 9.17) such a record would be confidential.

36.1. 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));

36.2. 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);

36.3. 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 an advance decision refusing life-sustaining treatment: *Barnsley Hospital NHS Foundation Trust v MSP*[46] and *An NHS Trust v D*.[47]

## G: The effect of an advance decision

37. 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:

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

37.1.1. 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

[46] [2020] EWCOP 26

[47] [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.

refusing treatment cannot prevent such treatment (although it should weigh heavily in the scales of the decision as to whether it should go ahead);[48]

37.1.2. 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)[49]; or (b) attracts the additional protections required by s.58A MHA 1983, namely (at present) ECT and associated medicines;[50]

37.1.3. 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;[51]

37.2. 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;[52] tortious liability for trespass could also attach. In the case of Brenda Grant,[53] who was provided with clinically assisted nutrition and hydration against the terms of her advance decision for 22 months, the Hospital Trust settled the claim and paid the family £45,000 in damages. Unfortunately (for these purposes) because the case resulted in a settlement, there is no reported judgment which spells out precisely the basis of the claim that was brought, although it is understood to have been framed in tort. 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.

37.3. In *Re AB (ADRT: Validity and Applicability)*,[54] Poole J observed that: *"MCA 2005 s25(2) sets out when an ADRT is not valid. A clinician is unlikely to know simply by looking at the document whether it has been subsequently withdrawn, whether it has been rendered invalid by the making of an LPA, or whether P has done anything else clearly inconsistent with the ADRT remaining their fixed decision."* Whilst the relevant guidance for clinicians in the Trust suggested that a

[48] Nottinghamshire Healthcare NHS Trust v RC [2014] EWCOP 1317.
[49] 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.
[50] Other treatments can be specified by regulations. Section 58A(5)(c)(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.
[51] 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 the treatments covered by s.57 are not emergency treatments, and hence it is difficult to envisage circumstances that would lead a doctor to considering invoking s.62 in respect of such treatments.
[52] The Code of Practice undoubtedly envisages (paragraph 9.57) that a failure to follow an advance decision could lead to a criminal charge of assault.
[53] BBC News: Payout after woman was kept alive against her will: https://www.bbc.co.uk/news/uk-england-coventry-warwickshire-42240148.
[54] [2025] EWCOP 20 (T3) at paragraph 53.6.

clinician presented with an ADRT should assume that it is valid unless they have doubts about its validity, Poole J observed that "[i]*t would be wise for clinicians presented with an apparent ADRT pro-actively to make enquiries - with the family or friends of P if possible - to discover whether there is any evidence that might call into question the validity of the ADRT under MCA 2005 s25(2).*"

37.4. 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);[55] 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. It seems to me further, that the professionals should, at a minimum, seek legal advice as to whether an application to the Court of Protection is required – not least because (depending upon the circumstances) an advance decision which does not comply with the formal requirements may nonetheless carry such weight as an indicator of the person's wishes in relation to treatment that it should dictate the outcome of the best interests decision that would need to be taken.

38. Finally, I note that, in *Re AB*, a case which at one stage looked as if it would require the court to consider the circumstances under which an advance decision had been made, Poole J emphasised that:

> *Any person who questions the authenticity of an ADRT which is ostensibly valid and applicable, or who is concerned that it was made under undue influence, must provide some reasonable grounds for raising those issues. The Courts will not sanction significant delays in resolving disputes about an ADRT without good cause.* [56]

## H: Engaging the assistance of the Court

39. 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.

40. 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)).

41. 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 *A Local Authority v E*, *X Primary Care Trust v XB* and *Re AB*:

41.1. *In Re E*, Peter Jackson J noted:

[55] Paragraph 9.58.
[56] Paragraph 53.9.

> *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.*[57]
>
> […]
>
> *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.*[58]

41.2. In *XB*, Theis J noted:

> *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.*[59]

41.3. In *AB*, Poole J identified that

> *Unless the ADRT is clear, questions as to its applicability under MCA 2005 ss25(3) and (4) and, if the treatment under consideration is life sustaining treatment, s25(5), require careful consideration and may require legal advice to be sought, as the RCP PDOC Guidelines 2020 recommend. If there is unresolved doubt or an ongoing dispute about the validity, applicability and/or authenticity of an ADRT, then it is likely that an application to the Court of Protection will be required. The Trust accepts that it should have made such an application in this case. Instead, CD made the application but her primary concern at the time of the application was not the ADRT but the parts of the Living Will and Letter to Presiding Judge dealing with contact with members of AB's family. Hence the issues concerning the ADRT itself were not promptly brought to the Court's attention until January 2025. The Trust had the resources and experience to make a prompt application for a determination of the validity and applicability of the ADRT and it should have done so. The need to make a prompt application*

[57] Paragraph 40.
[58] Paragraph 54.
[59] Paragraph 33.

> *when the validity, admissibility or authenticity of an ADRT are in doubt or dispute is clear: administering a treatment to a person who has refused it through an authentic, valid and applicable ADRT is as unlawful as is providing treatment to a person with capacity who refuses consent to it. MCA 2005 s26(5) allows treatment to be given "while a decision as respects of any relevant issue [relating to an apparent advance decision] is sought from the court" but that is not a reason to delay seeking a decision from the court.*[60]

42. Importantly, in the last of these cases Poole J also observed that:

> *Even if the ADRT is not valid and/or is inapplicable, it may yet be taken into account in a best interests decision. Furthermore, clinicians and P's family may agree that P's best interests coincide with their expressed wishes, even if those wishes were contained in an invalid or inapplicable ADRT. Even if there are disputes about the provision of some treatments, such as CANH, there may be agreement about others, such as CPR. Hence, ongoing consideration of best interests should not be put on hold whilst the validity and applicability (and indeed, authenticity) of an ADRT is being scrutinised. These are processes that should be followed in parallel with each other.*[61]

43. Such circumstances are also quintessentially those where the way forward (even if it is the way forward as regards best interests decision-making) is finely balanced that the Supreme Court in *NHS Trust v Y*[62] made clear required an application to court (at least in the case of life-sustaining treatments).

## I: Practical matters, the alternative of a lasting power of attorney (and deputies for completeness)

44. The discussion above gives rise to (at least two) important practical considerations:

    44.1. The first is that, in any case where it is possible that doubt might be thrown upon the person's capacity to make the advance decision at some later point, it is strongly advisable for a contemporaneous confirmation of capacity be obtained. I am very aware that many resent the idea that they should be required to undergo an assessment before they make an advance decision, and, rightly, point to the silence in the Act as to the need for such an assessment. Whilst recognising the philosophical force of this point, it is of little consolation for someone to be philosophically vindicated at point (by definition) they do not have capacity to decide whether or not to consent to the treatment in question and no contemporaneous evidence of their capacity exists. In some cases, the confirmation may need to follow a detailed assessment (the *E* case serving as an example), but in many cases, it will be simply be a case of getting a suitably qualified person to confirm that, having considered the capacity test within the MCA 2005, they have no reason to doubt that the person has capacity to make the decision;

[60] Paragraph 53.7.
[61] Paragraph 53.8.
[62] [2018] UKSC 46 at paragraph 125.

44.2. The second is that advance decisions can be very powerful, but very brittle. This means that it is always extremely important to consider putting in the advance decision a statement of values so that – in the event that (for whatever reason) the advance decision does not govern the decision to be made, those who have to make the decision as to whether or not to start or continue treatment can be guided in their best interests decision-making by an understanding of the person's views. The weight that will be placed on those views will depend upon the facts of the case, but can be essentially determinative if the reason for the 'failure' of the advance decision is essentially technical, and the document provides reliable evidence of the person's views.[63]

45. 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[64] to take health care decisions, including as to the refusal of life-sustaining treatment. Such authority must be expressly included in the instrument[65] and is subject to any conditions or restrictions in the instrument.[66]

46. Once registered,[67] 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,[68] subject to two important caveats:

    46.1. 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.[69]

    46.2. 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.[70]

47. Both ss.22 and 23 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

[63] See, for instance, *Barnsley Hospital NHS Foundation Trust v MSP* [2020] EWCOP 26.
[64] Or more than one.
[65] 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.
[66] Section 11(8)(b).
[67] A pre-condition to creation of an LPA: s.9(2)(b).
[68] Section 11(7)(a) makes clear that an LPA authorising a 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.
[69] Sections 22(3)(b)(i) and (ii), read together with s.22(4)(b).
[70] Section 23(2)(a).

example of where the court might seek to take an alternative course would be where the donor had undergone a religious 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.

48. If a person is considering appointing an attorney and also making an advance decision to refuse treatment, it is important to remember to get the sequencing right. An advance decision will automatically be invalidated if a power of attorney is **subsequently** created which confers authority on the donee(s) to give or refuse consent to the treatment to which the advance decision relates.[71] An advance decision could be made after the power of attorney has been created, at which point this would bind the hands of the attorney(s).[72]

49. For the sake of completeness, the same issues of sequencing do not arise in relation to deputies. A deputy can only ever be appointed by a court; depending on the terms of their appointment by the court they can make healthcare decisions, although they can never be given authority to refuse consent to the carrying out or continuation of life-sustaining treatment in relation to P.[73] The terms of the deputy's appointment should take into account any existing valid and applicable advance decision to refuse treatment known about at the point of their appointment; if the deputy discovers subsequent to their appointment that P had has made an advance decision, they should consider:

    49.1. Whether the advance satisfies the relevant statutory criteria, at which point the deputy's authority will be limited to actions consistent with that decision. They could not, for instance, seek to consent to treatment which is refused by that decision.

    49.2. Whether they need to return to court to get confirmation either as to the existence, validity or applicability of the advance decision, or (if none of these are in doubt) how it interacts with their own authority.

## J: Conclusion

50. 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; 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. The consequence, however, is that there are still some areas where it is necessary to read the runes of the MCA 2005 with particular care to ensure that the right route is taken.

[71] Section 25(2)(b). See also *N & Anor v E & Ors* [2014] EWCOP 27.
[72] Section 11(7)(b).
[73] Section 20(5).

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