

Commentary on advance decision to refuse treatment following the permanent loss of capacity to refuse LST

Summary: This advance decision refuses all life prolonging measures in the event that I lose capacity to decide whether to receive such interventions and am not likely to regain capacity in the future, or in the event that I am in a permanent vegetative or permanent minimally conscious state. It sets out a non-exhaustive list of interventions I refuse should the specified circumstances materialise. The sole (albeit temporary) qualification to the refusal of life prolonging measures is any intervention that would facilitate the retrieval and donation of my organs and tissues. The decision also contains a request for palliative care in the event that I experience pain and/or suffer in the period after I refuse life prolonging measures leading up to death. Finally, the decision provides a requirement for referral in the event of conscientious objection, and a section on disputes that may arise as to whether the decision is valid and applicable.

In what follows, I provide an explanation of the form (I) and the content (II) of my advance decision.

I. Form

There are a number of (free) advance decision templates available. Perhaps the best known is the Compassion in Dying advance decision.¹ Why, then, draft an advance decision from scratch? In part, I think the choice to write one's own advance decision rests on a hypothetical: how a clinician might respond either to a template or 'homemade' advance decision. If a clinician is more likely to respect a template advance decision (I set out reasons why this might be the case below), choosing a template may well be the best strategy for ensuring respect for one's wishes. If the converse is true, it may be better to write one's own advance decision. Moreover, I think there might be good reasons to write one's own advance decision even if template advance decisions stand a good chance of being respected generally.

One reason why using a template advance decision might be advantageous appeals to the idea of *familiarity*. The thought is that with a template one stands a good (or better) chance of having one's advance decision respected because it is something that a clinician may have seen before. Of

¹ Compassion in Dying, 'Advance Decision Pack' (2014) <http://www.compassionindying.org.uk/form/download-free-advance-decision> accessed 7 October 2014.

course, the first time a clinician encounters an advance decision on, for example, the Compassion in Dying template she may not know what it is, and/or that (if valid and applicable) it has identical legal effect to a valid contemporaneous refusal of treatment.² Hopefully upon this first encounter with an advance decision the clinician will take steps to establish how it should be evaluated, for example, by consulting the Mental Capacity Act 2005 (MCA 2005) (or the Act's Code of Practice),³ seeking advice from colleagues, the health authority solicitor etc. Over time, the idea is that by encountering advance decisions of the same form, clinicians may develop a somewhat streamlined procedure for evaluating their validity and applicability.⁴ Moreover, if a large proportion of one template advance decision are found to be valid and applicable, clinicians may become somewhat disposed *prima facie* to respect future iterations.

Of course, it will always be necessary to consider each advance decision individually, because a number of the grounds for invalidity/inapplicability depend not on the legal formalities,⁵ or what interventions are refused in which circumstances,⁶ but on what the individual has done subsequent to issuing her advance decision,⁷ or the presence of unforeseen circumstances that might reasonably be taken to undermine her decision.⁸ Moreover, an individual may have modified or added to the template. Notwithstanding this qualification, large-scale adoption of advance decision templates may simplify the task for clinicians and/or make non respect of advance decisions more difficult to justify.

One problem with the template strategy is that *familiarity* cuts both ways. Say a clinician encounters several or successive examples of a template advance decision that are found not to be valid and applicable. As a result, she may form the view that all advance decisions of this form lack legal effect (or at least be highly sceptical thereto), even if the reasons for invalidity or inapplicability relate not to the advance decision itself, but to the circumstances around it.⁹ It would be bad practice to hold this position, rather than scrutinise each advance decision on its own merits. However, section 26(2) of the MCA 2005 sets the threshold for liability for non-respect of an advance decision so high that it may be legally justifiable for clinicians to import past experience

² Mental Capacity Act 2005 (MCA 2005), s 26(1).

³ Department for Constitutional Affairs, *Mental Capacity Act 2005: Code of Practice* (TSO 2007) Chapter 9.

⁴ MCA 2005, ss 25(2), 25(4).

⁵ *Ibid* s 25(5), s 25(6).

⁶ *Ibid* ss 25(4)(a), 25(4)(b).

⁷ *Ibid* s 25(2).

⁸ *Ibid* s 25(4)(c).

⁹ This problem might be compounded when the clinician's other beliefs predispose her not to respect refusals of treatment. Arguably, there is wide scope for confirmation bias in the interpretation of advance decisions.

of an advance decision template into their decisions to continue treatment over a specific patient's advance decision (more on this below). If things went this way, the template strategy might be undermined, and one might have good reason to opt for a homemade advance decision, since it might not trigger the same conscious or subconscious disdain.

Another template issue might arise in virtue of choosing only the pro forma options. These options are designed to capture circumstances in which many people might wish not to undergo treatment. The possible danger here is that these options would be interpreted by a clinician as general circumstances in which one might refuse treatment, rather than her patient's own personally chosen circumstances. The idea is that the clinician would take her patient to have selected the 'best fit' case(s), rather than to have articulated her own beliefs. Thus the clinician might play on a purported *authenticity* problem in order to provide treatment. This might manifest in strict(er) interpretation of the inconsistent conduct and unforeseen circumstances criteria in the MCA 2005, which may result in invalidity and/or inapplicability respectively.¹⁰ This risk might be offset in two ways – either by adding to or amending a template advance decision, or by drafting an advance decision in one's own words. If one is confident that one can write an effective advance decision, it might be preferable to choose the latter option, since amending a template advance decision entails the risk of rendering it internally inconsistent.

The fears set out in the two preceding paragraphs might be dismissed as speculative; indeed, my concerns involve hypothetical considerations of what clinicians *might* do. Alternatively, it might be contended that whether a clinician initially respects an advance decision lacks practical significance, insofar as the MCA 2005 provides for judicial determination of questions relating to an advance decision's existence, validity, and applicability.¹¹ This latter claim is highly problematic. First, section 26(4) of the Act provides that the Court of Protection 'may make a declaration' as to the advance decision's legal effect. Thus someone has to seek the Court's assistance, and in the absence of challenge to the clinician's decision from loved ones, the relevant health authority will probably not initiate proceedings. Second, section 26(5) of the MCA 2005 permits the provision of life sustaining treatment and other measures 'to prevent a serious deterioration in P's condition' pending a decision of the Court of Protection. Since not all interventions persist over a significant interval of time,¹² it may be crucial whether a clinician respects her patient's advance decision of

¹⁰ MCA 2005, ss 25(2)(c) and 25(4)(c) respectively.

¹¹ Ibid s 26(4).

¹² cf CPR, surgery, blood transfusion, antibiotics, mechanical ventilation, clinically assisted nutrition and hydration, dialysis.

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her own accord, lest the opportunity for death be lost and replaced with precisely the circumstances that the individual wished to avoid.¹³ Moreover, even when the intervention(s) provided pending the Court's decision persist over time (and thus may be refused if the advance decision is upheld), one may well have experienced avoidable suffering prior to the Court's intervention. Thus I would argue that one's evaluation of the risks and benefits attached to using a template advance decision is of no small consequence. For me, the potential *familiarity* and *authenticity* issues counted against using a template, but alone these factors were probably not decisive. However, I had two additional reasons for writing my own advance decision.

The first appeals to the idea that *diversity* in advance decisions is desirable. In my view, clinicians should encounter a wide variety of advance decisions, written in both legal and layman's terms, with different layouts, handwritten and typed, etc. This is because dealing with a broad range of advance decisions, and encountering some advance decisions that perhaps look less 'official' can only encourage clinicians to appreciate that an advance decision's form is vastly less important than its content. Therefore, it is incumbent on those of us who have a detailed understanding of the law to write our own advance decisions; if one is able to write an advance decision that stands a reasonable chance of being respected, one probably should, even if there is some risk that it will not be accorded the same status as a template advance decision.

The second is that drafting one's own advance decision permits the cutting out of all extraneous information, and freedom to choose layout. I think these are significant advantages. My advance decision contains only the information that I wish to communicate to clinicians, and is one page long. In virtue of its economy, it is extremely clear, while nevertheless meeting the requirements of the MCA 2005. I submit that it should be a relatively simple matter for clinicians to ascertain whether my advance decision is valid and applicable to the circumstances that have arisen, or at least the document will not be a source of uncertainty.

By contrast, Compassion in Dying's advance decision runs to seven pages.¹⁴ There is a very broad menu of options: an individual can select from the pro forma refusal options (ss 1A-1D), or specify additional circumstances in which life prolonging measures are not to be provided (s 1E), or refuse of treatment in respect of a known illness (s 3), or detail things that she might wish the decision-maker to know (s 2), or provide an advance statement of wishes (s 4). She may also give details of

¹³ Jenny Kitinger and Celia Kitinger, 'The 'window of opportunity' for death after severe brain injury: family experiences' (2013) 35(7) *Social Health Illn* 1095

¹⁴ Compassion in Dying (n 1).

a lasting power of attorney (s 5) and her General Practitioner (s 6). Finally, she may have the advance decision witnessed by up to two people (section 7) (s 25(6) of the MCA 2005 requires only one witness). This is fantastic if one wants/is able to avail oneself of all these things. Arguably, however, there is much in the Compassion in Dying advance decision template that one might not want, but will be lumbered with nonetheless in the form of unfilled space. A further issue with the Compassion in Dying advance decision is that the legally binding refusals contained in sections 1 and 3 are on pages 2 and 4 of the template, whereas the witness and patient signatures (s 7) required to give the document legal validity are on page 7. In between, there are sections that do not have legal effect, and as such would not be subject to the MCA 2005 validity conditions. Somewhat confusingly, there is also a facility for the individual to sign that she has reviewed the advance decision on subsequent occasions on page 1. I argue that it would have been better to group the refusal sections with the signatures that give the document legal effect together, ideally at the beginning of the document. Moreover, any 'review declaration' should probably accompany the witness and patient signatures.¹⁵

I should stress that none of the above criticisms should affect the likelihood of a Compassion in Dying advance decision being held to be valid and applicable.¹⁶ Moreover, because the Compassion in Dying template is designed to be used by as many people as possible, it is perhaps unavoidable that there are many sections that may go unfilled. Nevertheless, I think it a fair charge that the document is inelegant and potentially confusing for clinicians.¹⁷ In sum, if one is confident manipulating the legal framework, one can probably produce an advance decision that is clearer and more individual than a template advance decision. In my case, this was the strongest reason to draft and design my own.

II. Content

Section 1 of my advance decision is straightforward. It informs the clinician that the document is an advance decision to refuse treatment, which is to apply in the circumstances detailed should I lack decision-making capacity in respect of medical intervention. It also identifies the law governing the validity and applicability of the decision in the United Kingdom. This is the MCA 2005 in England and Wales, and the common law in Scotland and Northern Ireland. Section 1(4)

¹⁵ I worry whether there is any value in declaring that one has reviewed one's advance decision without also having the document re-witnessed. It may be safer simply to re-execute one's advance decision at regular intervals.

¹⁶ Subject to the qualification in respect of internal consistency raised above.

¹⁷ I am aware that Compassion in Dying are working on a bespoke online advance decision portal. This service may avoid the criticisms outlined here.

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states that the decision is to apply even if refusal of treatment puts my life at risk, as required by section 25(5) of the MCA 2005.

Section 2 of the decision sets out the circumstances in which my advance decision applies, that is, the situations in which I will refuse all life prolonging measures (some of which are listed in section 3). The applicable circumstances are the loss of capacity in respect of life prolonging interventions coupled with it being unlikely (on the balance of probabilities) that I will regain this capacity in the future (s 2(1)(a)), and permanent vegetative state (PVS) or permanent minimally conscious state (PMCS) (s 2(1)(b)).¹⁸ Of course, the latter category is a subset of the former: correctly diagnosed individuals in a permanent vegetative or permanent minimally conscious state have enduringly lost the capacity to decide whether to permit medical intervention. Why include PVS and PMCS then? The circumstances in section 2(1)(a) are very broad indeed, and probably cover a range of situations in which clinicians (and others) might regard me to have a *life worth living*. Section 2(1)(a), therefore, risks offending clinical perspectives about lives of value, and thus being deemed inapplicable at the material time.¹⁹ I added section 2(1)(b) to make sure that, if nothing else, I no longer receive treatment once it has been determined that I am in PVS or PMCS. I am convinced that neither condition offers an individual a life that could be described as prudentially worth living, thus I would lose nothing as a result of refusing treatment in these circumstances.

Moreover, it made tactical sense explicitly to refuse medical intervention in the event of PVS or PMCS, since the legality in principle of abstention from treatment (including clinically assisted artificial nutrition and hydration) for these conditions is well-established.²⁰ The reported cases concern individuals who lack decision-making capacity, thus the rationale for the decision to abstain from treatment is that it is not in the individual's *best* interests to (continue to) receive treatment.²¹ This is distinct from the reason why valid refusals of treatment must be respected, which is that clinicians need permission (consent) to interfere with the patient's bodily integrity.²²

¹⁸ The Royal College of Physicians guidelines contain a classification of permanent vegetative state and an interim classification of minimally conscious state (pending further clinical evidence): *Prolonged disorders of consciousness: National clinical guidelines* (2013)

https://www.rcplondon.ac.uk/sites/default/files/pdoc_web_final_navigable_2014.pdf accessed 1 September 2014

¹⁹ It almost goes without saying that such conduct should be unlawful. The right to refuse medical treatment is unqualified; it exists even when one would in all likelihood go on to enjoy a life of value but for the refusal: *Re MB (An Adult: Medical Treatment)* [1997] 2 FCR 541 (CA).

²⁰ Thus clinicians might be relatively confident that abstention in such cases would not attract negative circumstances.

²¹ MCA 2005, ss 5, 4; *Airedale NHS Trust v Bland* [1993] 1 AC 789 (HL); *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67; *United Lincolnshire Hospitals NHS Trust v N* [2014] EWCOP 16.; *Re M (Adult Patient) (Minimally Conscious State: Withdrawal of Treatment)* [2011] EWHC 2443 (Fam).

²² *Re MB* (n 19).

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But the fact that my refusal coincides with what might be clinical consensus in respect of PVS and PMCS should somewhat dispose a clinician toward compliance, even if ultimately her respect for my wishes is motivated by considerations of best interests and not autonomy. Furthermore, because my view is that individuals in PVS and PMCS do not possess a life worth living, I believe that it would be a gross waste of scarce resources to provide medical interventions of no benefit to me. Those resources would be far better applied elsewhere.

Why did I choose the (likely enduring) loss of capacity in respect of life prolonging measures as a circumstance in which to refuse medical intervention? I could point to the (apparently) wide discrepancy in cognitive ability between me now, and me in the future who lacks capacity to decide whether to undergo lifesaving treatment. However, I'm not convinced that this difference gives a sufficient reason for my future self not to receive treatment, if once recovered, I would have a worthwhile life.²³ I think something that matters a great deal is the impact that my enduring loss of capacity would have on my loved ones. Presumably, I'm liked for who I am now (or perhaps a better, yet similar, future self); I worry that it would be hard for my loved ones to adjust to a radically different me. I also think it bad enough that they suffer through whatever event(s) precipitated my loss of capacity, and possibly the period before the need for life prolonging intervention arises. It would, in my view, be quite wrong to have loved ones endure my undergoing continuous or repeated lifesaving medical interventions when I will not recover to the person they knew. Moreover, I wouldn't want to burden them with my care, though I know it would be freely given. I'd rather that my loved ones live well.

Another significant consideration is that lifesaving medical intervention is not cost free. It is often invasive and inherently risky. I am quite concerned about the infliction of life prolonging interventions (such as those listed in s 3 of my advance decision) on individuals who lack the capacity to understand what is entailed. When I decide to undergo treatment now, I trade off its possible ills (side effects, complications etc) against the expected improvement in my health or wellbeing. It is this good in medicine that provides the reason to consent to interference with my bodily integrity. My worry in respect of individuals who lack capacity in respect of life prolonging interventions is twofold. First, unless an individual understands why an intervention may be beneficial, she may resist it; thus it may be necessary to use force, restraint and/or deprive an

²³ There are also complex issues of personal identity, with which I can't engage here. See eg Derek Parfit, *Reasons and Persons* (Clarendon Press 1984); Allen E Buchanan and Dan W Brock, *Deciding for others: the ethics of surrogate decision making* (Cambridge University Press 1989).

individual of her liberty in order to provide treatment.²⁴ This is potentially a source of suffering that cannot be balanced/justified by the restoration of health, particularly if as a result of the violation of her bodily integrity/liberty an individual develops a general fear of caregivers and health professionals. Second, even when force, restraint or deprivation of liberty are not involved, an individual may fail to understand that an intervention's action on her body is a means to some good end. This inability to rationalise the direct and side effects of treatment may also cause suffering. In sum, not wanting my loved ones to watch me undergo treatment that would not restore me to the person they knew, and not wanting to suffer treatment that I cannot comprehend, underlie my choice of (enduring) loss of capacity to decide in respect of life prolonging medical intervention as the circumstance in which I refuse all life prolonging measures.

Section 4 of my advance decision qualifies the blanket refusal of life prolonging measures in section 3, but only insofar as to permit any intervention that facilitates the donation and/or retrieval of my organs and tissues for transplantation. I believe that donation of one's organs after death is morally required. To this end, I would be quite happy to have my life prolonged a little, for example, by elective ventilation,²⁵ if it improved the viability and quality of my organs for transplantation.

Why did I request palliative care (any intervention to alleviate pain and/or suffering) in section 5(1)? The reasons I have offered in respect of the circumstances in which I would refuse life prolonging measures centre around the avoidance of burdening or causing suffering or distress to my loved ones, and avoiding any suffering that might be caused through the receipt or infliction of procedures that I cannot comprehend, and in respect of PVS and PMCS, not continuing in what I regard clearly to be a life not worth living. The common thread here is the avoidance of suffering. It would be consistent, therefore, to wish to forego, so far as practically possible, any suffering during the time after my advance decision is given effect and before my death. However, section 5(2) makes it clear that nothing in my request for palliative care should be taken to undermine the refusal of treatment contained in sections 1-3 of the document. Therefore, if the choice were between refusing life prolonging treatment, and suffering until death, I choose the former. Hopefully my clinician would not see palliative care and refusal as mutually exclusive options. The refusal of life prolonging measures merely extinguishes the clinician's duty to provide those interventions; I would argue that the duty to provide comfort care continues up until death.

²⁴ MCA 2005, ss 4A, 4B, 6

²⁵ See John Coggon, 'Elective ventilation for organ donation: law, policy and public ethics' (2013) 39(3) J Med Ethics 130.

What is the purpose of the conscientious objection provision in section 6 of the decision? I recognise a clinician might wish not to respect my advance decision on conscience (or moral) grounds. This might be because she regards refusal of life prolonging treatment as immoral (for example, insofar as it prematurely ends a life of intrinsic value), or because she regards *her respect* for my refusal to be immoral, without necessarily taking a position on the morality of my refusal. However, conscience does not provide a clinician with legal (or moral) authority to violate a patient's bodily integrity. Such an extensive right of conscience is not known to English law.²⁶ To the extent that there is a legally recognised right of conscience, it is limited to permitting clinicians to decline to *provide* patients with procedures that conflict with their personal beliefs and values.²⁷ With this in mind, section 6(2)(a) of my decision reiterates that I refuse all interventions in the applicable circumstances *irrespective* of my clinician's conscientious objection. In addition, section 6(2)(b) reminds my clinician that she has a professional obligation to refer me to another clinician who does not hold the same objection.²⁸

Section 7 relates to the regulation of disputes that may arise from my advance decision. Section 7(1) requests that in the event of disagreement as to the validity, and/or applicability of my advance decision, the competent health authority and/or my next of kin initiate proceedings in the appropriate Court (currently the Court of Protection). I am mainly counting on my loved ones; either to badger the health authority to seek the Court's assistance, or to make an application to the Court themselves. This is based on my (unverified) scepticism that health authorities would have arrangements for routine oversight of clinical decisions (not) to respect advance decisions.²⁹ Thus in cases in which the responsible clinician has 'indisputably' resolved that an advance decision is invalid and/or inapplicable, and there is no one to speak on the patient's behalf, that is likely to be the end of the matter. Yet clinicians may not possess the expertise necessary for successful interpretation of advance decisions (that we might expect, say, from a lawyer). Moreover, a clinician may wish not to respect an advance decision for reasons entirely unrelated to the document.³⁰

²⁶ *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam).

²⁷ General Medical Council, *Personal beliefs and medical practice* (2013) paras 8-16 http://www.gmc-uk.org/static/documents/content/Personal_beliefs.pdf accessed 18 October 2014; *Doogan v NHS Greater Glasgow & Clyde Health Board* [2013] CSIH 36.

²⁸ GMC *ibid* paras 12-13. The obligation may well be legal, in that the failure to refer may constitute a breach of the clinician's duty of care, on which a civil action for negligence might be founded, provided it can be shown that the patient suffers harm as a result of the breach. It is plausible that harm could be evinced, eg if P's bodily integrity is violated, and/or she experiences pain and/or suffering (loss of amenity) following the failure to refer.

²⁹ Of course, such arrangements would be highly desirable.

³⁰ eg beliefs related to the value of life, the goals of medicine etc

Section 7(2) requests that my next of kin seek a declaration that, prior to the issue of proceedings to establish whether my advance decision is valid and/or applicable,³¹ the failure to respect my advance decision constituted battery (which is both a civil wrong and a crime).³² It might be thought that the threat of legal action is inopportune, and that it would be better to be more collaborative/conciliatory. I am not convinced that the latter approach would be more successful; and, as a point of principle, one should not have to beg, thank, or be grateful to clinicians for respecting one's bodily integrity and the law.

Of course, at present, a battery action may have a slim chance of success, because of the way in which the liability conditions in the MCA 2005 are structured:

26 Effect of advance decisions

...

(2) A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.

(3) A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.

...

As Emily Jackson has observed, the effect of section 26(2) is that 'doctors will only face liability if they blatantly disregard what they know (or are 'satisfied') to be a valid [and applicable] advance decision ... [the doctor] can therefore ignore it with impunity'.³³ The clinician's liability is thus contingent on the veracity of her belief: did she know that the AD was valid and applicable, yet disregard it anyway? However, the liability threshold for non-respect of an advance decision need not be so undemanding. A court could read into section 26(2) of the MCA 2005 a requirement that the clinician's 'satisfaction' in respect of an advance decision's existence, validity and applicability be (objectively) reasonable. This would align the liability ground for non-respect of advance decisions with that of respecting an advance decision (s 26(3) MCA 2005), and thus disincentivise clinicians (to the extent that they are aware of the law) from taking the view that advance decisions are *prima facie* invalid and inapplicable. However, in order for legal change to

³¹ During which time a clinician will not be liable for any measures taken to preserve my life or health: MCA 2005, s 26(5).

³² Ms B (n 26); *Bland* (n 21) 891 (Lord Mustill)

³³ Emily Jackson, *Medical law: text, cases and materials* (3rd edn, 2013) 251.

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occur, someone needs to sue in battery when their advance decision is not respected. I hope that my next-of-kin would help me attempt to change this important element of the law on advance decisions.