Barnsley Hospitals NHS Foundation Trust v MSP [2020] EWCOP 26: The Need for Caution When Establishing the Wishes of Incapacitated Patients

I Introduction

In some respects, *Barnsley Hospitals NHS Foundation Trust v MSP*[1] is a paradigm of compliance with the United Nations Convention on the Rights of Persons with Disabilities 2006 (CRPD). Faced with a challenging decision over whether to withdraw life-sustaining treatment from a 34-year-old with complex abdominal problems, Mr Justice Hayden delivered a sensitive but forceful judgment, which placed substantial weight on the individual's previously expressed wishes, even in the face of a clear conflict with his clinical interests. In doing so, he emphasised the importance of looking at the decision from the patient's perspective, asking not whether continued life was objectively worthwhile, but whether the patient would regard it so.

While there is much to commend in this decision, three aspects of the decision warrant further examination. The first, and most important of these, concerns the evidential burden for establishing what the patient would want in such cases, particularly where, as here, there is a potential disparity between different previous expressions of the person's wishes. A second, and related issue, relates to why this ambiguity could not have been resolved by delaying the decision until MSP regained capacity and could express his wishes himself, in line with the principle enshrined in section 1(3) Mental Capacity Act 2005 (MCA) that all practicable steps be taken to support the person to make a decision himself before embarking on a best interests assessment. Finally, I examine a broader point, raised by this case, that even the most carefully drafted and applicable advance directives fail, consistently, to be implemented. I therefore finish by exploring the need for a nation-wide register for advance directives to ensure that all directives meet the formality requirements, and come to the attention to the doctor at the relevant time.

The central argument in this paper, is that while there is clear value to embracing the empowering ethos underpinning the CRPD, cases such as this demonstrate a need for some caution when ascertaining and giving effect to the person's previously expressed wishes, and

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[1] [2020] EWCOP 26.

underly the importance of involving the person, wherever possible, in the decision being taken about them.

II The Decision

Barnsley Hospitals NHS Foundation Trust v MSP[2] (*MSP*) concerned whether or not a Trust should continue to provide ITU support, including ventilation, nutrition and hydration, to a 34-year-old man with a complex abdominal history. The application had initially been made to Mr Justice Hayden as an Out of Hours judge, but he considered 'the consequences of the decision too profound to be resolved at an emergency out of hours hearing',[3] and so the case was heard fully a few days later.

The patient, MSP, had suffered from serious gastrointestinal problems for 10 years which had resulted, amongst other interventions, in a stoma being formed in October 2019. MSP strongly objected to having a stoma and so it was removed some months later at his instigation. During this time, he also signed an advance directive, in which he sought to refuse the formation of any future stoma "that is expected to be permanent or with likelihood of reversal of 50% or under",[4] even where it was necessary to sustain or prolong life. However this failed to comply with the requirement set out in section 25(6) MCA that the directive be signed by a witness,[5] and consequently was not valid.

Not long after this, he became ill once again, this time with an obstruction of the small bowel. Mr M, the gastroenterologist who was treating MSP, considered his condition life threatening, necessitating the urgent formation of a new stoma. Surprisingly, given his clearly expressed objections to having a stoma in the past, MSP consented to it. His consent was, the judge accepted, capacitous at the time MSP gave it, albeit that it may well have been influenced by Mr M's clear 'optimism' that the stoma would be capable of being reversed in the future. Although the judge did not engage in detail with what the prospect of the stoma being reversed now was, underpinning the application was a seeming acceptance that it was now remote, and Mr M appeared to accept when giving evidence that the possibility of MSP being able to feed himself by his mouth was 'speculative', the likelihood of which 'he did not feel able to evaluate'.[6] Consequently, the Trust applied to the Court of Protection to determine whether, in circumstances where there was evidence that the patient would not

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[2] [2020] EWCOP 26.

[3] Ibid, [14].

[4] Ibid, [9].

[5] Ibid, [19].

[6] Ibid, [42].

wish for life-sustaining treatment to continue, the Trust ought to continue to provide ITU support to him or not. At the time of the hearing, MSP was sedated and ventilated. He had an endotracheal tube and was breathing spontaneously with the support of the ventilator, with stable oxygen levels. Even if ventilation was withdrawn, it was therefore likely that MSP would continue to survive. Accordingly, the court had to consider whether or not it was 'in his best interests for artificial nutrition and hydration to be withdrawn' from him.[7]

In determining his best interests, Mr Justice Hayden attached great significance to the previously expressed wishes of MSP. Drawing on Lady Hale's oft-quoted passage in *Aintree University Hospital NHS Trust v James*,[8] that the judge must "see the patient as an individual with his own values, likes and dislikes, and to consider his best interests in a holistic way",[9] he emphasised the importance of approaching the assessment from the patient's perspective, asking not whether a reasonable person would regard MSP's life with a stoma as worthwhile, but how MSP himself would feel about it.

In respect of this question, the evidence, from his family, two of MSP's previous doctors, and his recent 'carefully crafted' advance directive, was striking in its strength and consistency. Although his advance directive was not binding on the court (not having been witnessed), it provided strong evidence of his previously held wishes which was of 'significant relevance when evaluating MSP's best interests.'[10] The view expressed in this was strongly supported by his family and previous doctors. His families' portrayal of him was of an intelligent, handsome and lively young man,[11] determined 'to conceal the impoverishment of his health and to present himself to the world as competent and active.'[12] The stoma had, by all accounts, been 'corrosive to his self-esteem',[13] affecting his relationships with women and running entirely contrary to his perception of himself. Indeed his father expressed the fear that 'if his son was permitted to recover consciousness and discover his own plight', he would kill himself.[14]

His doctors meanwhile, also noted his strong objections to having a stoma. Dr I, who had treated MSP for some time, was described as 'surprised that MSP had agreed to the stoma',[15] while Dr W, who had met him on a number of occasions, was 'perplexed by how it

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[7] Ibid, [19].
[8] [2013] UKSC 67.
[9] Ibid, [26].
[10] Ibid.
[11] Ibid, [15].
[12] Ibid, [15].
[13] Ibid, [7].
[14] [2020] EWCOP 26, [41].
[15] ibid, [11].

was that MSP had given his consent.'[16] The 'preponderant evidence' thus pointed 'strongly to MSP not wishing to live with a stoma, or, as he put it, with any "ongoing medical treatment that will prevent [him] from living independently, either long term or indefinitely"'.[17]

It was against this backdrop that Mr Justice Hayden considered the significance of MSP's consent to the insertion of the stoma, just days earlier. In light of the evidence of MSP's previously expressed wishes, he appeared to accept the argument, put forward by Counsel for the Applicant Trust, that this 'authorisation' was 'predicated on Mr M's optimism that the stoma could, potentially, be reversed'.[18] If, by contrast, Mr M 'been pessimistic, as to the prospects of a reversal', Mr Justice Hayden held, 'there is little doubt in my mind that MSP would have rejected the procedure and chosen to die.'[19] Although this did not mean that 'this court should correct the error by bringing about the death which MSP would prefer to life with an irreversible stoma',[20] the judge nonetheless concluded that MSP would not wish to continue to live with an stoma and so would wish that artificial nutrition and hydration were withdrawn from him, leading to his death. Accordingly it was in his best interests to authorise this the withdrawal of all but palliative care for MSP.

III Commentary

The decision in *MSP* is striking in that it concerns a young man who was not suffering from any terminal, or even fatal, illness and who would likely regain consciousness in the near future, without any substantial long term impairment to his cognitive capacities. In this sense, it is a far cry from the withdrawal of life-sustaining treatment cases which are usually brought before the Court of Protection, which often involve seriously brain damaged or disabled patients with little or no prospect of recovery.[21] Indeed reading Mr Justice Hayden's judgment in this case, it is hard to believe that it was just ten years ago that the Court of Protection first contemplated whether it was even lawful to withdraw treatment from someone in a minimally conscious state.[22] *MSP* thus illustrates the seismic shift in approach to best interests determinations which has occurred in the last decade, which has seen

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[16] Ibid, [12].

[17] [2020] EWCOP 26, [41].

[18] Ibid, [42].

[19] Ibid, [46].

[20] Ibid, [46].

[21] See, for example, *W v M and others* [2011] EWHC 2443 (Fam); *United Lincolnshire NHS Trust v N* [2014] EWCOP 16; *Sheffield Teaching Hospitals NHS Foundation Trust v TH & Anor* [2014] EWCOP 4; *M v Mrs N* [2015] EWCOP 76 (Fam); *Briggs v Briggs (No. 2)* [2016] EWCOP 53; *Salford Royal NHS Foundation Trust v Mrs P* [2017] EWHC EWCOP 23.

[22] *W v M and others* [2011] EWHC 2443 (Fam).

increasing weight being attached to the wishes and feelings of the individual, even where this conflicts with the clear clinical assessment of their best interests.[23]

In many respects, therefore, the decision may be heralded as cementing the shift towards a more empowering understanding of best interests, which places the individual at the heart of the process, and seeks to decide in a way which reflect *their* values and priorities. In doing so, it goes a long way towards compliance with the CRPD,[24] Article 12(4) of which requires its signatories (including the UK) to undertake to 'ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person.' While many have been critical of the extent to which the current provisions in section 4 MCA comply with this,[25] the application of best interests in *MSP,* which contains a strong element of substituted judgement[26] (whereby the decision-maker makes the decision which they find "that the patient, acting reasonably, himself would have made" [27]), would certainly seem to 'respect' the individual's wishes and preferences. Indeed, Mr Justice Hayden was clear that when applying the best interests test, 'the objective is to reassert P's autonomy and thus restore his right to take his own decisions in the way that he would have done had he not lost capacity.'[28]

There is certainly much to commend in the judgment, which paints a vivid picture of MSP as an independent and successful young man, struggling to come to terms with the

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[23] See, for example, *Aintree University Hospital NHS Trust v James* [2013] UKSC 67; *Re M (Best Interests: Deprivation of Liberty)* [2013] EWHC 3456 (COP); *Westminster City Council v Sykes* [2014] EWCOP B9*; Newcastle-upon-Tyne Foundation Trust v LM* [2014] EWCOP 454; *Wye Valley NHS Trust v B* [2015] EWCOP 60; *Briggs v Briggs (No. 2)* [2016] EWCOP 53; *A Clinical Commissioning Group v P and TD* [2019] EWCOP 18.

[24] UN General Assembly, *Convention on the Rights of Persons with Disabilities: resolution adopted by the General Assembly*, 24 January 2007, A/RES/61/106.

[25] See for example, Committee on the Rights of Persons with Disabilities, *General Comment No 1 (2014) Article 12: Equal Recognition Before the Law* (adopted at the Eleventh session of the Committee, 31 March –11 April 2014, Geneva, CRPD/C/GC/1) at [21]; . Martin et al, 'Three Jurisdictions Report: Towards Compliance with CRPD Art. 12 in Capacity/Incapacity Legislation across the UK' (2016) Essex Autonomy Project, 40. Available at: < https://autonomy.essex.ac.uk/wp-content/uploads/2017/01/EAP-3J-Final-Report-2016.pdf >; G. Richardson, Mental Disabilities and the Law: From Substitute to Supported Decision-Making? (2012) 65 *Current Legal Problems*, 333–354, 348; . Bartlett, 'The United Nations Convention on the Rights of Persons with Disabilities and Mental Health Law' (2012) 75 MLR 752; 766; E. Jackson, 'From 'Doctor Knows Best' to Dignity: Placing Adults Who Lack Capacity at the Centre of Decisions About Their Medical Treatment' (2018) 81(2) MLR 247–281, 266.

[26] For an explanation of how best interests includes an 'element' of substituted judgement, see *Re G(TJ)* [2010] EWHC 3005 in which Morgan J explains that through its provisions in s4(6) MCA, best interests could include an 'element' of substituted judgement, and in the absence of any countervailing factors, respect for the person's wishes could define what would be in their best interests [at 55]. This was also the conclusion reached by the Law Commission in the pre-legislative consultation period for the MCA, who rejected adopting a purely 'substituted judgement' approach in favour of an objective 'best interests' approach with an 'element' of substituted judgement: see *Mental Incapacity*, Law Com No 231 (HMSO, 1995), 3.25,

[27] *Re G(TJ)* [2010] EWHC 3005, [13]. For a further discussion of this, see A. Buchanan & D. Brock. *Deciding for Others* (Cambridge: Cambridge University Press, 1989), 112.

[28] [2020] EWCOP 26, [24].

consequences of his illness. As Mr Justice Hayden explained, MSP emerged from the accounts of his family

> as a highly intelligent man, voraciously interested in the world, politics and affairs. He was an A star student, hard-working and respected by his colleagues at school, university and in the workplace. He is 6ft 3, handsome and meticulous in his appearance. His step-sister has gently suggested that he might have been prone to more than a little male vanity. Recently, struggling to walk any distance, MSP bought himself a pair of designer sunglasses so that he could look smart and confident when driving in his car. His mother told me that he spent two hundred pounds on them. Though she plainly considered this extravagance, I sensed that she delighted in what she saw as her son's engagement in the world. This, in my assessment, is not mere vanity but a reflection of MSP's determination to conceal the impoverishment of his health and to present himself to the world as competent and active.[29]

Throughout the judgment, he emphasised the importance of looking at matters from the patient's perspective (the fact that the 'vast majority' of people with stomas learn to live with them was irrelevant, if MSP would find the prospect 'unbearable'[30]), and it is evident that the judge went to some effort to attempt to understand the character and motivations of MSP,[31] and why it was that a stoma was so intolerable to him. The judgment is also notable in its emphasis on MSP's emotional and psychological welfare, even at the expense of his medical interests, which would have pointed clearly in favour of prolonging treatment. In fact very little attention is given to his clinical prognosis at all in the judgment, which focuses squarely on what MSP's wishes would be.

Yet while this decision is admirable as a high-water mark among best interest decisions for prioritising the patient's previously expressed wishes, two of its aspects warrant further analysis. The first of these concerns what the evidential burden is for establishing what the patient would want in cases such as this, especially where conflicting evidence might give rise to doubt. The second questions whether this ambiguity ought to have been resolved by involving MSP in the decision, either through rousing him from his sedation or delaying the decision.

(a) The evidential burden when establishing what P would want

Mr Justice Hayden was clear in his desire to determine, as far as possible, what MSP would have wanted in the situation at hand; and he appeared to have little doubt in his mind that on

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[29] [2020] EWCOP 26, [15].

[30] Ibid, [7] and [41].

[31] The same is also true of his judgment in *M v Mrs N* [2015] EWCOP 76 (Fam), where he engaged in a detailed and intimate examination of Mrs N's values and personality, drawing on the accounts of her family, and calling on evidence going back to when she was 18 years old; and in *Sheffield Teaching Hospitals NHS Foundation Trust v TH & Anor* [2014] EWCOP 4.

the facts, this would have been to end his life. Whether he was correct in this regard is, of course, a question of fact — and one which, following the death of MSP, one can never know for certain. Yet given the enormity of the consequences of this determination, it is regrettable that more attention was not given in this case to the evidential standard that must be met before the judge draws a conclusion such as this.

Section 4(6) MCA is clear that when determining the person's best interests, the decision-maker ought to consider, so far as is reasonably ascertainable, 'the person's past and present wishes and feelings'; the 'beliefs and values that would be likely to influence his decision if he had capacity', and any 'other factors that he would be likely to consider if he were able to do so'. Nothing in the Act, however, sets out how certain the decision-maker ought to be about what the person's wishes and feelings are, before attempting to give effect to them. Given Mr Justice Hayden's approach to the best interests determination, which came close (like other judges before him[32]) to substituted judgement, this issue is important. As Scott Kim and Alexander Ruck Keene explain, the 'more that the approach under the MCA becomes the exercise of substituted judgment, the more problematic it may appear that decision-makers are not required to explain, and justify, their certainty level.'[33] In other words, the more weight that is attached to the person's wishes in the determination of their best interests, the more important it is that the judge is sure about what those wishes are. If, as in this case, the judge puts a very substantial amount of weight on the person's wishes, one would suppose that the judge ought to be very confident in his assessment, especially where, as here, it results in the death of a person in circumstances where this is clearly contrary to their clinical interests. Yet how certain is certain? Must the judge have no reasonable doubts as to what the person would have wanted (the criminal law standard); or must he or she merely think it more likely than not that the person would have acted in this way (the civil standard)? Or is it a different standard entirely?

Although Mr Justice Hayden did not engage with this question in *MSP*, there is some limited discussion of it in earlier cases. In one of the earliest of these, *M v N*,[34] Mr Justice Hayden suggested that the presumption in favour of life could be rebutted by the patient's wishes, where they are expressed with 'similar cogency and authenticity' to an advance

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[32] See, for example, Mr Justice Charles in *Briggs v Briggs (No. 2)* [2016] EWCOP 53; and Mr Justice MacDonald in *A Clinical Commissioning Group v P and TD* [2019] EWCOP 18.

[33] S. Kim and A. Ruck Keene, 'A new kind of paternalism in surrogate decision-making? The case of *Barnsley Hospitals NHS Trust Foundation Trust v MSP'* (2020) *J Med Ethics* 1-6, 4.

[34] [2015] EWCOP 76.

directive.[35] He did not, however, elaborate on when exactly this would be the case. Mr Justice Charles engaged with this question more explicitly in *Briggs v Briggs (No. 2),*[36] when he commented that when striking the balance between self-determination and the sanctity of life,

> if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained *with sufficient certainty* it should generally prevail over the very strong presumption in favour of preserving life [emphasis added].[37]

Yet later on in the judgment, he 'deliberately' refused

> to set out *how convinced the court has to be about what P would have decided* if he or she was able to do so because, in my view, the weighing exercise is so case and issue sensitive and is not a linear or binary exercise, and because here I am sure (in the sense that I have no reasonable doubt) on the decision that Mr Briggs would have made if he was able to do so. [emphasis added][38]

So, although the judge had to be 'sufficiently certain' of what P would want, precisely what would be required to satisfy this standard would have to be determined on a case by case (or issue by issue) basis. In that case, however, the issue did not arise, since the judge (echoing the criminal law standard of proof), had 'no reasonable doubt' as to what P would want.

This idea was then picked up on again by Mr Justice MacDonald in *A Clinical Commissioning Group v P and TD,*[39] when he stated that 'where P's wishes can be ascertained with *sufficient certainty* in this way, they should generally prevail over the very strong presumption in favour of preserving life' [emphasis added].[40] In that case, once again, the judge considered the standard was met as he was satisfied 'on the balance of probabilities' that 'prior to becoming incapacitated, P expressed a clear and firmly held view that she would not want to be kept alive in circumstances in which she now finds herself.'[41] She had stated on one prior occasion that she would not wish to be kept alive on a life-support machine — a view that the judge regarded as consistent with her general character and outlook. With respect, this would seem to be a relatively low threshold to meet before being 'sufficiently certain' of their wishes. In fact, it would seem closer to the standard of belief required for doctors to *avoid* liability for withholding or withdrawing treatment in accordance with an invalid or inapplicable advance directive,[42] which is rightly set lower (at

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[35] Ibid, [31].

[36] [2016] EWCOP 53.

[37] Ibid, [62].

[38] Ibid, [74].

[39] [2019] EWCOP 18.

[40] Ibid, [71].

[41] Ibid, [65].

[42] s26(3) MCA provides that a doctor cannot be *liable* for the consequences of withholding or withdrawing treatment if he or she 'reasonably believes' that an advance directive exists which is valid and applicable to the treatment.

whether they have a 'reasonable belief'), since it dictates when a doctor ought to be held *liable* for taking a certain decision, and not whether that decision represents the 'best' outcome overall for the patient.

In *MSP,* Mr Justice Hayden did not engage with the question at all, merely stating that there was 'compelling and cogent' evidence of his wishes and feelings,[43] and making no reference to his degree of certainty, or to what factors or 'issues' might be relevant to the level of certainty required. Yet, unlike in *Briggs*, in *MSP* there was at least one reason why the judge may have had doubts as to what MSP wanted, namely the fact that MSP had, just days earlier, and at a point when he had capacity, chosen to consent to the stoma. In determining that he would have wished not to continue to live with the stoma, the judge was thus going against his most recent, explicit and capacitous decision. Mr Justice Hayden dismissed the relevance of this in *MSP* as resting purely on the optimistic portrayal by Mr M of the prospect that the stoma was reversible. Yet given the clear significance of this, it is regrettable that the judgment does not contain a more detailed consideration of either what *exactly* Mr M said to MSP prior to him consenting to the stoma, *or* what the evidence now was that the stoma would be irreversible in the future. Mr Justice Hayden stated that 'whether the history of the case justified Mr M's optimism is logically irrelevant'.[44] With respect, however, this could well be relevant. In MSP's advance directive, which Mr Justice Hayden acknowledges evidences 'considerable thought to the scope of interventions' he wished to refuse,[45] MSP stated that he would refuse the formation of a stoma if it was 'expected to be permanent *or with a likelihood of reversal of 50% or under*' [emphasis added]. It follows therefore, that were the likelihood of reversing the stoma to have been 50% or more, MSP might very well have consented to it. The extent to which his decision to consent to the stoma can be reconciled with his previously expressed wishes, as opposed to evidencing a possible change of heart, therefore rests on the fact that Mr M presented the chance that the stoma might be reversible as exceeding 50% *when in fact* it was under 50%.

It is, of course, an essential facet of autonomy that a patient is entitled to change their mind about what they wish to happen in their medical care, particularly when they have capacity, and there is ample evidence that people's treatment preferences can change over their time and in different contexts.[46] Certainly, the apprehension of imminent death is apt to

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[43] [2020] EWCOP 26, [46].

[44] Ibid, [46].

[45] Ibid, [9].

[46] See for example, PH Ditto et al, 'Stability of older adults' preferences for life-sustaining medical treatment' (2003) Health Psychol 22: 605–15; PH Ditto et al, 'Context changes choices: a prospective study of the effects

provoke a change in perspective, and even the most resolute patients may waiver when faced with a choice between certain death, and an uncertain treatment course. It may well be that there *was* evidence presented that MSP consented *only* because he considered the prospect of the stoma being reversible as being over 50%, when it was in fact substantially less, and that this finding of fact was simply not recorded in the judgment. Yet without this evidence, it is doubtful that the patient's recent capacitous act of giving consent can really be dismissed as failing to represent his 'true' wishes. If his consent to the stoma *cannot* be dismissed, then it follows that there is some room to question what MSP would have wanted in these circumstances. Consequently, the question of exactly how certain the judge must be about what the person would want becomes crucial.

It certainly seems unlikely on the facts of this case that Mr Justice Hayden could have described himself as having 'no reasonable doubts' as to what MSP would want. The question is then, what level of doubt ought to be tolerated in decisions where the consequences are as profound as this? Mr Justice Charles suggested in *Briggs* that this would depend on the specific case and issues.[47] At the very least, however, there ought to be some elaboration by future courts on what the issues or factors ought to affect the level of doubt tolerated. Kim Scott and Alexander Ruck Keene helpfully suggest two potential factors: 'the medical consequences of the proposed decision', and 'how reliably can the surrogate decision-maker apply the presumed or stated values and preferences of the patient to the current decision'.[48] Both ought, rightly, to affect the degree of certainty the judge has. Greater judicial guidance on this issue would certainly be welcome.

(b) Resumption of Capacity

Given the potential doubts that the judge might have had over MSP's wishes, it is regrettable that the judgment does not contain any discussion of when MSP was likely to regain capacity in the future, or whether it would have been clinically possible to rouse him from his sedation, in order that he might have been able to clarify his wishes himself. It may well be that this was contemplated in the hearing, but dismissed as a possibility. Nonetheless given

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of hospitalization on life-sustaining treatment preferences' (2006) *Med Decis Making* 26(4): 313-22. It is worth noting here that there is some evidence that those who have signed advance directives typically have more stable preferences: see for example, M Danis et al, 'Stability of choices about life-sustaining treatments' (1994) Ann Intern Med 120: 567–73; MPS van Wijmen et al, 'Stability of end-of-life preferences in relation to health status and life-events: A cohort study with a 6-year follow-up among holders of an advance directive' (2018) *PLoS One* 18;13(12).

[47] [2016] EWCOP 53, [62].

[48] S. Kim and A. Ruck Keene, 'A new kind of paternalism in surrogate decision-making? The case of *Barnsley Hospitals NHS Trust Foundation Trust v MSP'* (2020) *J Med Ethics* 1-6, 4.

the stipulation in section 1(3) Mental Capacity Act 2005, that “a person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success”, a discussion of why the decision could not be delayed, or his sedation lifted would have been welcome.

Indeed in some respects this decision represents a missed opportunity to examine how s1(3) MCA ought to apply in situations where, as here, the person is temporarily unconscious, but likely to regain consciousness in the future. Where the consequences of the decision are as significant as this one, and where there is some disparity between different previous expressions of the person’s wishes, the imperative to take every step to allow the person to take it themselves would seem to be especially important. And while there was some evidence presented that awareness of his condition might have caused some distress to MSP,[49] it is not clear that this, or the patient’s wish to not be involved in such a decision, goes to the question of whether it is ‘practicable’ for them to take the decision themselves.

Even accepting MSP lacked capacity, sections 4(3) and 4(4) MCA required the best interests decision-maker to consider whether MSP was likely to regain capacity,[50] and to encourage him to participate in the decision-making process where possible.[51] At the very least, the judgment should have included greater exploration of his ability to participate, with an explicit focus on ss1(3) and 4(4) MCA.

(c) Enhancing the Role of Advance Directives

The facts of *MSP* also raise a broader concern. MSP had, in fact, drafted a carefully thought-out advance directive to cover exactly the kind of situation he now found himself in, which contemplated both the triggering conditions for the directive and the sorts of interventions he wished to refuse. Indeed such was the detail of the document, that it even included the music he would wish to be played if he were to fall into a coma.[52] The advance directive was not valid, and so its utility in this case was limited, used only as evidence of his prior wishes for the purposes of determining his best interests. Yet the very fact that the directive fell to be

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[49] For example, his father suggested that ‘if his son was permitted to recover consciousness and discover his own plight’, he would kill himself at [2020] EWCOP 26, [41].

[50] Section 4(3) MCA 2005 states that the decision-maker must consider ‘(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and (b) if it appears likely that he will, when that is likely to be’.

[51] Section 4(4) MCA 2005 states that the decision-maker must ‘so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.’

[52] [2020] EWCOP 26, [10]

used in this way raises a number of concerns about the legal and administrative regime that currently surrounds advance directives.

At the point of time where the initial decision to consent to the stoma was to be made, the advance decision was inapplicable, since MSP retained capacity. It also failed to meet the formal requirement contained in section 25(6) MCA that it be witnessed.[53] Even if this had not been the case, however, the evidence suggests that the directive, which was held only by MSP himself and three family members, was never brought to the attention of the treating doctor.[54] If it had been, Mr M was clear that the conversation surrounding the formation of the stoma may have been 'of a different complexion.'[55] This case is therefore an illustration of a broader problem afflicting advance directives, namely the difficulties in ensuring that the treating doctor knows about it at the relevant time. A similar issue arose in *NHS Cumbria CCG v Rushton*,[56] where, despite 'fastidiously' complying with the provisions, and even sending the advance directive to her GP to keep on her file,[57] the patient's directive was not produced in the hospital at the relevant time,[58] and so a PEG tube was inserted against her clearly expressed written directive. These examples do not stand alone, in the UK or elsewhere. Evidence from the Centre for Disease Control in the United States suggested that about half of those aged sixty or older had an executed advance directives, and yet 'between 65 and 76 percent of physicians whose patients had an advance directive were not aware that it existed.'[59]

I have argued elsewhere for the possibility of creating a national registry for advance directives,[60] similar to that seen in Spain,[61] and in various states of the US.[62] As Allison Hughes has pointed out, this would enable there to be 'a secure repository where advance directives can be quickly and easily retrieved by healthcare providers or named proxies.'[63]

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[53] Mental Capacity Act 2005, s25(6).
[54] Ibid, [35].
[55] Ibid, [43].
[56] [2018] EWCOP 41.
[57] Ibid, [20].
[58] Ibid, [24].
[59] N. Aldrich and W. Benson, 'Advance Care Planning: Ensuring Your Wishes Are Known and Honored If You Are Unable to Speak for Yourself' (2012) CTRS. FOR DISEASE CONTROL & PREVENTION 1, available at <https://www.cdc.gov/aging/pdf/advanced-care-planning-critical-issue-brief.pdf>
[60] C. Auckland, 'Protecting Me from my Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia' (2018) 1 *Medical Law Review* 73-97
[61] Law no. 41/2002 on Patient's Autonomy and on the Rights and Obligations Concerning Health Information (Spain), Article11.
[62] For example in Arizona (Ariz. Rev. Stat. Ann. §36-3291); California (Cal. Prob. Code §4800–4806); Idaho (Idaho Code Ann. §39-4515); Louisiana (La. Rev. Stat. Ann. §40:1299.58.3); Maryland (Md. Code Ann., Health— Gen. §5-619 to 626) and Montana (Mont. Code Ann. §50-9-501 to 505).
[63] A. Hughes, 'State Advance Directive Registries: A Survey and Assessment' (2009) BIFOCAL Bar Associations in Focus on Aging and Law, Vol. 31(2), 36.

Registries could require that directives registered with it use a standardised proforma,[64] so as to ensure clarity over the triggering conditions of the directive and what treatments it applies to, and providing for a 'statement of values' to help inform decisions which do not fall directly within the remit of the directive. Registries could also scrutinise all directives on registration for compliance with legal requirements, as occurs in various state repositories in the US.[65] This would avoid the second problem raised in *MSP*, that the directive was not appropriately witnessed. It would ensure that directives comply with the legal safeguards contained in the MCA, and that discrepancies were picked up at the point of registering the advance directive, not, as is currently the case, at the point of its implementation, when the person already lacks capacity and so it is too late to address them.

Such a registry, which might operate in a similar way to the Organ Donation Register, would, of course, be costly and burdensome to administer. Two points must be borne in mind. Firstly, based on current statistics, the register is unlikely to include a very high number of advance directives. These suggest that only 4% of the population of the UK has written an advance directive,[66] equating to 2.66 million people. The Organ Donation Register, by contrast, currently has 25.2 million people on it, or 39% of the population. Secondly, given that advance directives only exist to refuse medical interventions, at least some of the costs involved in operating the system would also be recouped through the timely rejection of unwarranted medical treatment, which, particularly in the context of intensive end of life treatment, can be very expensive. A cheaper, less complicated way of making directives accessible would be to include advance directives in electronic health records. However given the existing difficulties in achieving integration of these between different Trusts, aptly demonstrated by the fact that Mrs Rushton's advance directive did not come to light at the relevant time in *Rushton*,[67] despite being kept on her file at the GP,[68] a national registry would seem to the best way of ensuring the accessibility (and applicability) of advance directives in similar future decisions.

IV Conclusion

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[64] For a more detailed discussion of this, see C. Auckland, 'Protecting Me from my Directive: Ensuring Appropriate Safeguards for Advance Directives in Dementia' (2018) 1 *Medical Law Review* 73-97, 88-91.

[65] For example Maryland (Md. Code Ann., Health— Gen. §5-619 to 626) and Montana (Mont. Code Ann. §50-9-501 to 505).

[66] Accessible at < http://compassionindying.org.uk/wp-content/uploads/2014/11/YG-Archive-Compassion-in-Dying-results-120913.pdf> accessed 11th December 2020.

[67] [2018] EWCOP 41.

[68] Ibid, [20].

There is much to commend about the empowering and person-centred approach to best interests taken in *Barnsley Hospitals NHS Foundation Trust v MSP*.[69] However, given the weight attached to the patient's previously expressed wishes in the judgment, it is regrettable that Mr Justice Hayden did not engage in more detail with the evidential burden which had to be met before he would say with confidence what the patient would have wanted, or with the evidence in *this* case which might have affected that judgment. Given the consequence of this decision was to withdraw life-sustaining treatment from a young man in his thirties who was not suffering from a life-limiting condition and who had capacitously consented to life-saving treatment just days previously, this omission is significant. It is hoped that, as judges increasingly defer to the person's wishes and feelings in determining their best interests, there will be greater clarity on the question of what standard of evidential certainty they must meet before they draw conclusions on what the person would have wanted, as well as when it will be appropriate to delay such a decision so as to enable the person to take it themselves when they regain capacity.

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[69] [2020] EWCOP 26.