



Neutral Citation Number: [2020] EWCOP 26

Case No: 1360935T

**IN THE COURT OF PROTECTION**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 01/06/2020

**Before :**

**THE HONOURABLE MR JUSTICE HAYDEN**  
**VICE PRESIDENT OF THE COURT OF PROTECTION**

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**Between :**

**Barnsley Hospital NHS Foundation Trust**  
**- and -**  
**MSP**  
**(by his litigation friend the Official Solicitor)**

**Applicant**

**Respondent**

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**Bridget Dolan QC** (instructed by **DAC Beachcroft**) for the **Applicant**  
**The Official Solicitor, in person, as litigation friend to MSP**  
Hearing dates: 1<sup>st</sup> June 2020  
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**Approved Judgment**

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

.....

THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered following a remote hearing conducted on a video conferencing platform and attended by the press. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the names and addresses of Respondent, his family and the treating doctors must not be published. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Covid-19 Protocol: This judgment was handed down remotely by circulation to the parties' representatives by email and release to BAILII. The date and time for hand-down is deemed to be at 2pm on Wednesday 3<sup>rd</sup> June 2020.

**Mr Justice Hayden :**

1. On the evening of Friday 29<sup>th</sup> May 2020, whilst on duty as the Out of Hours Judge, I received an application on behalf of Barnsley Hospital NHS Foundation Trust. The application, presented by Ms Dolan QC, related to MSP, a 34-year-old man with a complicated abdominal history which has caused him to have significant gastrointestinal problems for approximately 10 years. The issue framed in the application is whether the Trust should continue to provide ITU support or withdraw treatment other than palliative care.
2. Historically, it has not been possible to join the Official Solicitor in these urgent Out of Hours applications. The offices of the Official Solicitor have not been able to identify the resources to facilitate it. Ms Sarah Castle has, since her appointment as Official Solicitor, been determined to remedy this situation. As of last week, she is now able to provide Out of Hours cover for serious medical treatment cases, personally supported by a number of senior members of her team. This application is the first time the Official Solicitor has been called upon in these circumstances and I should like to express my gratitude to her. I should also add that I have found her involvement to be helpful and, I have noticed that the family of MSP have plainly welcomed her input.
3. For more than a decade MSP has had painful and complex abdominal problems. In July 2013 he had a gastric ulcer which required a laparotomy and significant care in the Intensive Care Unit (ICU) afterwards. The primary gastroenterology diagnosis is unclear but MSP has experienced bleeding from the bowel, chronic abdominal pain and poor absorption of nutrients.
4. In October 2019, MSP underwent surgery where an ileostomy was formed. There was a significant prolapse in February 2020, which it is clear MSP found to be very distressing. At MSP's request the stoma was reversed on 14<sup>th</sup> May 2020. Though I will develop this, in my reasoning below, it requires to be recorded here that MSP utterly loathed life with a stoma.
5. Following surgery MSP returned home to his mother and father, where he has lived throughout his life, apart from his time at university. Sadly, but not entirely unsurprisingly, as I read the evidence, MSP returned to the hospital a few days later with very significant abdominal pain and sepsis. There was also acute distention of the abdomen. A CT scan was undertaken, revealing an obstruction of the small bowel and a drain was inserted which released three litres of faecal fluid. MSP's position was plainly very grave. Mr M, who is the consultant gastroenterological surgeon on duty, responsible for MSP's care at this admission, impressed upon his patient that his condition was life threatening and that he required a stoma to be formed immediately.
6. There is no doubt that MSP expressed his consent to the stoma being inserted. This consent however seemed entirely contrary to his unambiguous rejection of the stoma, expressed bluntly to three consultants with whom he had discussed it. It also appeared entirely inconsistent with everything he had said to his mother, father and step-sister on the point. Significantly, on 4<sup>th</sup> February 2020 MSP had written a carefully crafted Advance Directive which he had copied to his parents and to his step-sister. Outside the hospital setting these were the only three people who knew MSP had a stoma. He did not even wish his grandmother to be told.

7. Many people require a stoma to be fitted and I have no doubt that the vast majority make the necessary accommodations to ensure that it does not unnecessarily inhibit their enjoyment of life or become an impediment to their personal and sexual relationships. However, this was simply not the case with MSP. There is powerful evidence that as a young man in his thirties who, as his sister has said, “*knew he was good looking*”, MSP could never accept life with a stoma. No amount of support, love or understanding could change MSP’s mind. The stoma, it seems to me, ran entirely contrary to MSP’s perception of who he is. Its existence was corrosive to his self-esteem.
8. The Advance Decision, which MSP entitles ‘Advanced Directive’ contains the following paragraphs:

*“To avoid any doubt, and unless stated to the contrary below, I confirm that the following refusals of treatment are to apply, even if my life is at risk or may be shortened as a result.*

*I refuse ALL medical treatment or procedures/interventions aimed at prolonging or artificially sustaining my life in the event that any or all of the following occur:*

- I have an imminently life-threatening physical illness or condition from which there is little or no prospect of recovery (in the opinion of two appropriately qualified doctors);*
- I suffer serious impairment of the mind or brain with little or no prospect of recovery together with a physical need for life-sustaining treatment/interventions (in the opinion of two appropriately qualified doctors);*
- I am persistently unconscious and have been so for at least 52 weeks and there is little or no prospect of recovery (in the opinion of two appropriately qualified doctors);*
- I have been diagnosed as being in a persistent vegetative state or minimally conscious state and have been so for at least 52 weeks and there is little or no prospect of recovery (in the opinion of two appropriately qualified doctors).”*

9. It is clear that MSP gave considerable thought to the scope of the interventions that might fall to be considered. His document continues:

*I refuse elements of treatment that, while potentially necessary for sustaining or prolonging life, will result directly or indirectly in:*

*“The loss of function of both hands, through amputation or physiological changes, including three or more fingers on any one hand;*

*The formation of a stoma, through an ileostomy, colostomy, urostomy or similar, that is expected to be permanent or with likelihood of reversal of 50% or under;*

*The permanent disfigurement of my face through the removal of sections of my skull or other maxillofacial structures;  
The requirement for ongoing medical treatment that will prevent me from living independently, either long-term or indefinitely, i.e. the requirement for ongoing kidney dialysis or similar.”*

10. A further illustration of the care and thought that went into the document is demonstrated by the meticulous detail relating to music to be played in the event that MSP fell into a coma. In her evidence, his mother told me that MSP had described to her violent and frightening dreams when he had been ventilated on ICU previously in 2013. He discussed these with his mother in detail and returned to them on a number of occasions. This illuminates the close and loving relationship between the two and reinforces my impression of her as determined, as she puts it, to be a voice for her son. His mother tried to unravel and make sense of the dreams. In the course of the last few months I have been made aware, from a number of very senior consultants, that these frightening and often violent dreams are sometimes a feature of the experience of patients who have been ventilated. It is recognised as “ICU syndrome” and I have heard it compared to Post Traumatic Stress Disorder (PTSD). The intrusive nature of ICU can never be underestimated. MSP told his mother that he had nightmares of being raped. Sensibly, to my mind, she helped her son to understand that this was probably a reaction to the many tubes that had to be inserted into him. The music MSP set out in a playlist in his Advanced Directive document was selected to relax him if he found himself in this situation again. The music is eclectic, ranging from The Smiths (introduced to him by his father) to the Adagio for Strings, by Samuel Barber. The document also makes provision for music at his funeral as well as incorporating a number of diffident suggestions that strike me as empathetic to the family who he is contemplating leaving behind. I emphasise all these details because they are, to my mind, indicators of the enormous amount of time and thought that had been given to this document.
11. At the hearing on Friday evening, I heard from Dr I, who had been treating MSP for some time. He was surprised that MSP had agreed to the stoma, which was formed surgically on 27<sup>th</sup> May 2020. Today, I have heard from Dr W, Consultant Anaesthetist and clinical lead for ICU, who has met with MSP on a number of occasions and who has plainly formed an impression of MSP’s temperament and personality
12. Dr W, who I found to be kind and respectful to MSP’s parents, when they questioned him and professionally sensitive and reflective in his evaluation of his patient’s situation, was also perplexed by how it was that MSP had given his consent. Dr W appeared on the conferencing platform, on which we are presently constrained to hear cases, in his scrubs. He had sent a message to the Court in advance of the hearing apologising for not being able to change, no apology was required. Dr W gave his evidence first and at the conclusion of it I told him that I was grateful to him and that he was free to leave court. As an afterthought, conscious of how busy he is, I said that if he preferred to remain and listen to the evidence he was entirely free to do so. It was clear to me that he wanted to understand whether there had been some seismic change in MSP’s thinking in relation to the stoma. It was not a surprise to me, having listened to his evidence, that Dr W chose to stay to hear the evidence of Mr M. In fact, Dr W remained throughout the entire case, including the closing submissions. Mr M also stayed throughout the hearing.

13. This application revolves around MSP's own expressed wishes. It requires them to be scrutinised, not only in the context of what he has said and written but by reference to the way he has lived his life, his personality and his beliefs. His parents have been the conduits through which this information has been placed before the Court. The Official Solicitor, Ms Castle has paid her tribute to their courage as parents. I should like to echo this. Both were adamant that their responsibility was to tell me not what they wanted but what their son wanted. It was clear that the two are entirely different, though they were controlled and phlegmatic in their evidence.
14. On Friday evening, having heard from Dr I and both parents, I made declarations that were designed to keep MSP comfortable until the case could be heard more extensively and with less pressure on time. The parents readily appreciated that the issues presented by this case were far too grave and the consequences of the decision too profound to be resolved at an emergency out of hours hearing. I did, however, endorse the suggestion that over the weekend no attempt at resuscitation should be made in the event of cardiac arrest.
15. In her evidence on Friday evening MSP's mother was, entirely understandably, emphasising the most positive aspects of her son's personality, of which there is no shortage of material. Today, she gave a much more well-rounded account of him. MSP's father added information as and when necessary. His contributions were unfailingly helpful and pertinent. MSP emerges from their account 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. As I have recorded above, MSP was determined to conceal the stoma from all but the three people closest to him.
16. MSP had his own particular demons. His mother told me that at university he went through a period of self-harming and was ultimately diagnosed as bi-polar. Though it took a little time to get the balance of his medication right, this was eventually achieved and he has remained on anti-depressant medication which has been effective for him. In candid terms MSP's mother told me that her son was very popular with girls and had a great many girlfriends. Following the stoma MSP withdrew from any real attempt to forge intimate relationships. Though, his mother told me, he previously enjoyed beer and red wine, in moderation at weekends, this no longer agreed with him and he had started drinking gin rather to excess and every day. Despite his wish to recover vitality, MSP continued to smoke heavily and in the face of his parents' unconcealed opposition to it.
17. Over the weekend I was told that MSP's parents were able to meet up with their daughter/step-daughter. They sat outside in the garden, at a safe social distance, and they discussed MSP. It was obvious that this conversation was full of warmth, love and humour. It is, I have noticed, a feature of the evidence of those families who are doing

their best to help the court understand the nature and personality of their incapacitous relative, that humour so frequently erupts into the description. His mother told me a number of stories about MSP that pointed to him having a lively, sometimes slightly raucous sense of humour. It is also important to recall that when, in response to the evidence, I referred to MSP as “obviously a good looking lad” his mother corrected me. He is not “a lad” she insisted, he is a grown man, intelligent, articulate, a graduate and a respected professional. She was entirely right to refocus my thoughts. There is no doubt, in my mind, that he had come to a clear and entirely settled decision that he was not prepared to contemplate life with a stoma or indeed any significant life changing disability. It is not for me, or indeed anybody else, to critique those views or beliefs, but merely to identify them. They are a facet of MSP’s broader personality, the expression of which is integral to his own personal autonomy.

18. Before I consider the evidential significance of MSP’s conversation with Mr M, it is necessary to set out the applicable legal framework in which the facts of this case fall to be considered. As I have commented in other cases the framework of the applicable law is settled and relatively easy to state. The application of it to the circumstances of the individual case, in this highly fact specific jurisdiction, is invariably challenging.
19. Undoubtedly there are procedural deficiencies in MSP’s Advance Decision, for example, the signature was not witnessed by a second person as required. I shall consider these below but, in any event, all agree that document has significant relevance when evaluating MSP’s best interests. For the avoidance of doubt, I should make it clear that MSP is currently sedated and ventilated. He has an endotracheal tube in situ and is breathing spontaneously with the support of the ventilator. Dr W told me that over the weekend a third sedative agent was added as MSP had been intermittently reaching for his ET tube. He is receiving 25% oxygen and his oxygen level is stable. The arterial blood gas demonstrates a metabolic acidosis, the origin of which is presently unknown but could be due to significant biliary fluid losses from his ileostomy. He is supported nutritionally with total parenteral nutrition. Dr W emphasises that MSP is receiving very little organ support and accordingly, if the hospital were to withdraw life sustaining care this would mean extubating MSP and permitting him to breathe on his own. Given that he is breathing spontaneously with only a small amount of support, at the moment, it is conceivable that MSP would not die because of this, unless sedated to the extent that his breathing and cough reflexes are suppressed. As Dr W puts it, with great clarity, “*there is very little support to withdraw otherwise*”. Accordingly, if MSP’s wishes are to be given effect, what requires to be identified is whether it is in his best interests for artificial nutrition and hydration to be withdrawn.
20. Self-evidently, MSP is presently incapacitous. Identifying the best interests of an incapacitated person is to be determined in accordance with s.4 MCA 2005 the key parts for these purposes provide:

*“(2) The person making the determination [for the purposes of this Act what is in a person's best interests] must consider all the relevant circumstances and, in particular, take the following steps.*

*(3) He 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.*

...

*(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.*

*(6) He must consider, so far as is reasonably ascertainable— (a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity), (b) the beliefs and values that would be likely to influence his decision if he had capacity, and (c) the other factors that he would be likely to consider if he were able to do so.*

*(7) He must take into account, if it is practicable and appropriate to consult them, the views of— . . . (b) anyone engaged in caring for the person or interested in his welfare, . . . as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).”*

21. Baroness Hale in **Aintree University Hospital NHS Trust v James [2013] UKSC 67** (at para [26]) described this section as putting an “*emphasis on the need to see the patient as **an individual** (my emphasis), with his own values, likes and dislikes, and to consider his best interests in a holistic way”*”.
  
22. In **Briggs v Briggs [2017] 4 WLR 37**, Charles J considered that where best interests in respect of life sustaining treatment is in issue the “*default position for incapacitous persons is founded on the sanctity of life and so the strong presumption that lives that have value should be continued by life-sustaining treatment”*. However, whilst there is considerable weight or indeed, a strong presumption in favour of the prolongation of life, it is manifestly not an absolute. As Charles J went on to say in *Briggs* (at para 7):

*“In all the circumstances of this case I have concluded that the weightiest and so determinative factor in determining what is in Mr Briggs' best interests is what I am sure he would have wanted to do and would have concluded was in his best interests. And so, for him, his best interests are best served by giving effect to what he would have been able to dictate by exercising his right of self-determination rather than the very powerful counter arguments based on the preservation of his life.”*



In coming to this view Charles J was echoing the holistic application of the best interests test, concerned with enabling the court to do for the patient that which he could do for himself if he had full capacity, articulated by Baroness Hale in *Aintree* (above).

23. Delivering the judgment of the Supreme Court Baroness Hale stated:

*“[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.”*

*“[45] Finally, insofar as Sir Alan Ward and Arden LJ were suggesting that the test of the patient's wishes and feelings was an objective one, what the reasonable patient would think, again I respectfully disagree. The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that "It was likely that Mr James would want treatment up to the point where it became hopeless". But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.”*

24. When applying the best interests tests at, s.4(6) MCA, the focus must always be on identifying the views and feelings of P, the incapacitated individual. 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.
25. The weight to be attributed to P's wishes and feelings will of course differ depending on a variety of matters such as, for example, how clearly the wishes and feelings are expressed, how frequently they are (or were previously) expressed, how consistent P's

views are (or have been), the complexity of the decision and how close to the borderline of capacity the person is (or was when they expressed their relevant views). In this context it is important not to conflate the concept of wishes with feelings. The two are distinct. Sometimes that which a person does not say can, in context, be every bit as articulate as wishes stated explicitly.

26. Ms Dolan highlights the decision of Munby J (as he then was) in **Re M, ITW v Z [2009] EWHC 2525(COP) [2011] 1WLR 344** (at para 35):

*“I venture, however, to add the following observations:*

*(i) First, P's wishes and feelings will always be a significant factor to which the court must pay close regard: see Re MM; Local Authority X v MM (by the Official Solicitor) and KM [2007] EWHC 2003 (Fam), [2009] 1 FLR 443, at paras [121]-[124].*

*(ii) Secondly, the weight to be attached to P's wishes and feelings will always be case-specific and fact-specific. In some cases, in some situations, they may carry much, even, on occasions, preponderant, weight. In other cases, in other situations, and even where the circumstances may have some superficial similarity, they may carry very little weight. One cannot, as it were, attribute any particular a priori weight or importance to P's wishes and feelings; it all depends, it must depend, upon the individual circumstances of the particular case. And even if one is dealing with a particular individual, the weight to be attached to their wishes and feelings must depend upon the particular context; in relation to one topic P's wishes and feelings may carry great weight whilst at the same time carrying much less weight in relation to another topic. Just as the test of incapacity under the 2005 Act is, as under the common law, 'issue specific', so in a similar way the weight to be attached to P's wishes and feelings will likewise be issue specific.*

*(iii) Thirdly, in considering the weight and importance to be attached to P's wishes and feelings the court must of course, and as required by section 4(2) of the 2005 Act, have regard to all the relevant circumstances. In this context the relevant circumstances will include, though I emphasise that they are by no means limited to, such matters as:*

- a) the degree of P's incapacity, for the nearer to the borderline the more weight must in principle be attached to P's wishes and feelings: Re MM; Local Authority X v MM (by the Official Solicitor) and KM at para [124];*
- b) the strength and consistency of the views being expressed by P;*

*c) the possible impact on P of knowledge that her wishes and feelings are not being given effect to: see again Re MM; Local Authority X v MM (by the Official Solicitor) and KM, at para [124];*

*d) the extent to which P's wishes and feelings are, or are not, rational, sensible, responsible and pragmatically capable of sensible implementation in the particular circumstances; and*

*e) crucially, the extent to which P's wishes and feelings, if given effect to, can properly be accommodated within the court's overall assessment of what is in her best interests."*

27. Nothing requires to be added to those very clear observations. In **Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67** the Supreme Court made it clear that the court below had been wrong to focus on what "*the reasonable patient*" would decide, and emphasised that the patient's own wishes and feeling must be properly considered: "*the things which were important to him... should be taken into account because they are a component in making the choice which is right for him as an individual human being.*"
28. At para [44] of Aintree, Baroness Hale said that "*As was emphasised in Re J (1991), it is not for others to say that a life which the patient would regard as worthwhile is not worth living*". It is axiomatic that the corollary must equally be true i.e. it is not for others to say that a life they would regard as tolerable would be considered to be so by P. As Jackson J put it in **Wye Valley NHS Trust v B [2015] EWCOP 60** at [9], "*Where a patient is suffering from an incurable disability, the question is whether he would regard his future life as worthwhile.*"
29. Ms Dolan draws my attention to a number of cases following Aintree which have considered the weight to be placed on the wishes and feelings of an incapacitous adult in the best interests' assessment. She highlights my own judgment in **M v N (by her litigation friend, the OS), Bury Clinical Commissioning Group [2015] EWCOP 9**, where I observed (at paras 28 & 30):

*"...where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's 'best interests'. Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them.*

*Finally, I would observe that an assessment of P’s wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed non-verbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P’s views from what he may have done in the past in circumstances which may cast light on the strength of his views on the contemplated treatment. Mr Patel, counsel acting on behalf of M, has pointed to recent case law which he submits, and I agree, has emphasised the importance of giving proper weight to P’s wishes, feelings, beliefs and values see *Wye Valley NHS Trust v B.*”*

30. In **Cumbria Clinical Commissioning Group v Miss S and Ors [2016] EWCOP 32 I** made the following observation:

*“I cannot over-emphasise the importance of listening to the family who ultimately know the patient’s personality best. That is not to say that their wishes and views should be determinative, but it is extremely important that they are heard and their observations given appropriate weight.”*

31. Sometimes the evidence to inform the decision is simply not there or, alternatively, not sufficiently cogent to be relied on (see **Abertawe Bro Morgannwg University Local Health Board v RY & Anor [2017] EWCOP 2**)
32. It is also important, as all the advocates agree, to have regard to paragraphs 5.31 – 5.35 of the Code of Practice when making decisions about life-sustaining treatment:

*“5.29 A special factor in the checklist applies to decisions about treatment which is necessary to keep the person alive (‘life-sustaining treatment’) and this is set out in section 4(5) of the Act. The fundamental rule is that anyone who is deciding whether or not life-sustaining treatment is in the best interests of someone who lacks capacity to consent to or refuse such treatment must not be motivated by a desire to bring about the person’s death. ...*

*5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person’s best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment. Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of*

*the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests.*

*5.34 Where a person has made a written statement in advance that requests particular medical treatments, such as artificial nutrition and hydration (ANH), these requests should be taken into account by the treating doctor in the same way as requests made by a patient who has the capacity to make such decisions. Like anyone else involved in making this decision, the doctor must weigh written statements alongside all other relevant factors to decide whether it is in the best interests of the patient to provide or continue life-sustaining treatment."*

33. Ms Dolan submits:

*"the authorities are clear: the judge must seek to arrive at his objective assessment of whether continuation of life sustaining treatment is in **this** patient's best interests. However, those interests must be seen through the prism of the subjective position of the patient."*

I agree.

34. In her written submission Ms Dolan observes:

*"In the present case the court must consider and should give considerable weight to MSP's views that have been consistently expressed to his family and healthcare professionals and were recorded in writing at a time when he had full capacity. He has been clear throughout he would not want to live with a permanent stoma. That when he had capacity on 28 May, when facing death from sepsis, he accepted an operation that gave him the possibility of life without a permanent stoma does not militate against that remaining his choice."*

I regard this as an important submission and will return to it below.

35. I indicated above that the Advance Directive was not procedurally compliant. During the course of the hearing I discovered that it was not brought to the hospital's attention until Mr M had operated. It is not entirely clear why, save that this is a family in great distress, coping with challenging circumstances which are exacerbated by the necessary privations of social distancing in the face of the COVID-19 pandemic. Crucially, at the time of MSP's admission nobody had any reason to doubt that he lacked capacity, indeed he did not at that stage.

36. In **NHS Cumbria CCG v Rushton [2018] EWCOP 41** I emphasised the importance of compliance both with the statutory provisions and the codes of practice when preparing an Advance Decision. The combination of statute and code intends to strike a balance between the respect for adult autonomy and the risk that a person might find himself locked into and advance refusal which he or she might wish to resile from but can no longer do so. I highlighted the profound consequences of non-compliance with the requirements addressed in **W v M & S & A NHS Primary Care Trust [2012] COPLR 222; Re D [2012] COPLR 493**.
37. It strikes me as useful to reiterate these provisions, built upon the common law, which require to be met in order for the decision to be valid and applicable.

***“24 Advance decisions to refuse treatment: general***

*(1) "Advance decision" means 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.*

*(2) For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.*

*(3) P may withdraw or alter an advance decision at any time when he has capacity to do so.*

*(4) A withdrawal (including a partial withdrawal) need not be in writing.*

*(5) An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).*

***25 Validity and applicability of advance decisions***

*(1) An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—*

*(a) valid, and*

*(b) applicable to the treatment.*

*(2) An advance decision is not valid if P—*

*(a) has withdrawn the decision at a time when he had capacity to do so,*

*(b) has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or*

*(c) has done anything else clearly inconsistent with the advance decision remaining his fixed decision.*

*(3) An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.*

*(4) An advance decision is not applicable to the treatment in question if—*

*(a) that treatment is not the treatment specified in the advance decision,*

*(b) any circumstances specified in the advance decision are absent, or*

*(c) there are reasonable grounds for believing 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.*

*(5) An advance decision is not applicable to life-sustaining treatment unless—*

*(a) 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, and*

*(b) the decision and statement comply with subsection*

*(6) A decision or statement complies with this subsection only if—*

*(a) it is in writing,*

*(b) it is signed by P or by another person in P's presence and by P's direction,*

*(c) the signature is made or acknowledged by P in the presence of a witness, and*

*(d) the witness signs it, or acknowledges his signature, in P's presence.*

*(7) The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable.”*

38. The force of the Advance Decision is given effect by s.26 MCA 2005 in these terms:

*“(1) If P has made an advance decision which is—*

*(a) valid, and*

*(b) applicable to a treatment,*

*the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.*

*(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.*

*(4) The court may make a declaration as to whether an advance decision—*

*(a) exists;*

*(b) is valid;*

*(c) is applicable to a treatment.*



*(5) Nothing in an apparent advance decision stops a person—*

*(a) providing life-sustaining treatment, or*

*(b) doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition, while a decision as respects any relevant issue is sought from the court.”*

39. In **NHS Cumbria CCG v Rushton** (Supra), at para 16 I summarised the core features required to ensure the validity of the Advance Decision:

- “i) full details of the person making the Advance Decision including the date of birth, home address and any distinguishing features;*
- ii) the name and address of the person's GP and whether they have a copy of the document;*
- iii) a statement that the document should be used if the person ever lacks capacity to take treatment decisions;*
- iv) a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;*
- v) the date the document was written;*
- vi) the person's signature (or the signature of someone the person has asked to sign on their behalf and in their presence);*
- vii) the signature of the person witnessing the signature, if there is one.”*

40. For completeness the following paragraphs of the Code require to be set out:

*“9.25 Section 4(10) states that life-sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. This decision will not just depend on the type of treatment. It will also depend on the circumstances in which the healthcare professional is giving it. For example, in some situations antibiotics may be life-sustaining, but in others they can be used to treat conditions that do not threaten life.*

*9.26 Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural*

*mechanisms that control hunger and thirst and requires clinical monitoring. An advance decision can refuse ANH. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.*

*9.27 It is very important to discuss advance decisions to refuse life-sustaining treatment with a healthcare professional. But it is not compulsory. A healthcare professional will be able to explain:*

- *what types of treatment may be life-sustaining treatment, and in what circumstances*
- *the implications and consequences of refusing such treatment (see also paragraph 9.14).*

*9.28 An advance decision cannot refuse actions that are needed to keep a person comfortable (sometimes called basic or essential care). Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth. Section 5 of the Act allows healthcare professionals to carry out these actions in the best interests of a person who lacks capacity to consent (see chapter 6). An advance decision can refuse artificial nutrition and hydration.”*

41. It is in the context of this framework that I must evaluate what now truly are MSP's 'best interests'. The preponderant evidence points strongly to MSP not wishing to live with a stoma or, as he puts it, with any “*ongoing medical treatment that will prevent me from living independently, either long term or indefinitely*”. Whilst this document is not binding as an Advance Decision, it nonetheless represents a clear and eloquent expression of MSP's wishes and feelings. Nor, as I have stated above, does it stand alone. It is reinforced by the choate and consistent evidence of MSP's parents, his step-sister (communicated via the parents) and the clear evidence of three consultants, each of whom was left with no doubt at all that MSP would not want to live either with the stoma or TPN and that the combination of both would be unbearable for him. MSP's father told me that if his son was permitted to recover consciousness and discover his own plight, he thought he would “*kill himself*”. This is something his father fears most of all. It was at this point, in his evidence, that this strong and determined father faltered and was momentarily unable to maintain his emotional composure.
42. As Ms Dolan points out the conversation with Mr M and the authorisation by MSP of the stoma was predicated on Mr M's optimism that the stoma could, potentially, be reversed. In evidence Mr M readily agreed that he had been optimistic, notwithstanding the history of the earlier reversal. If I may say so, Mr M struck me as a person with an optimistic and positive attitude to his patient. This was illustrated in his evidence, when he said that though the stoma would never be reversible, it may be that parenteral nutrition may not be necessary lifelong. It struck Mr M that the survival of the large bowel, albeit with multiple adhesions, may leave open the possibility, at least theoretically, of enteral feeding i.e. by mouth, at some point in the future. Mr M agreed this was speculative and did not feel able to evaluate the likelihood of it.

43. The conversation between MSP and Mr M requires to be set in its context, having regard to the evidence holistically. Mr M knew nothing of the ‘Advance Directive’, he agreed that his conversation would have been of a different complexion if he had been aware of this. I emphasise this was nobody’s fault; the document had not been produced. At the time of the conversation, MSP is described as very unwell and septic, he was also receiving a high grade and level of analgesia. I also factor in Mr M’s optimism concerning the potential reversibility of the stoma, the force of which will undoubtedly have been communicated to MSP. I agree with Ms Dolan that in these circumstances MSP’s consent is not necessarily inconsistent with all he has said, nor with the document that has been the focus of scrutiny. What MSP did not want was to find himself in the position he now is. Whether the history of the case justified Mr M’s optimism is logically irrelevant. MSP rejects life with an **irreversible** stoma and in terms which are unambiguous and consistent. In these circumstances he has made it clear that he rejects all medical treatment or procedures or interventions that artificially sustain his life. Manifestly, this extends to parenteral feeding.
44. As Ms Castle submits, and I accept, the issue in this case is respect for MSP’s autonomy. His expressed wishes and feelings, she analyses, weigh most heavily in the balance, to the extent that they are determinative here. In other words, the presumption of preservation of life is rebutted by the countervailing weight to be afforded to MSP’s autonomy. Ms Dolan has, as her arguments set out above illustrate, concentrated on the consistency and cogency of MSP’s clear views. Logically her arguments lead to the same conclusion advanced by the Official Solicitor. However, Ms Dolan stops short of reaching a conclusion and, though this is her application, on behalf of the Trust, she adopts what she articulates as a position of neutrality. She advances no other course, nor has she suggested that the sanctity of life or the presumption of promoting life has not been displaced. Her careful and skilful arguments, properly analysed, lead only to the conclusion reached by the Official Solicitor.
45. It is important to confront what all this means in the medical context. The Code of Practice highlights the importance of this exercise in the holistic assessment of best interests. There is a real prospect that MSP will survive ventilation. The prospects of that are said to be somewhere between 60 to 70 percent. Accordingly, Dr W considers that if MSP’s wishes are to be given effect, there should be withdrawal of artificial nutrition and hydration with continued sedation which, ultimately, will compromise respiration and lead to MSP’s death.
46. It is important to break these issues down. Whilst I have highlighted the less than optimal circumstances in which MSP gave his consent to Mr M for the stoma, I do not consider that the evidence rebuts the presumption that MSP was capacitous at the time. If MSP has yielded to an overly optimistic prognosis of reversal which, as we know, proved to be unfounded, he may have means of legal redress. I am not in a position, on the evidence available to me, to know whether or not Mr M should have been more circumspect in his advice. Had he been pessimistic, as to the prospects of a reversal, there is little doubt in my mind that MSP would have rejected the procedure and have chosen to die. This does not mean that this court should correct the error by bringing about the death which MSP would prefer to life with an irreversible stoma. This is, in my judgement, runs contrary to s4 (5) MCA which prohibits an evaluation of “best interests” which is motivated by a desire to bring about death. The intensity of the focus on MSP’s rejection of life with the stoma occludes the fact that he has been equally

clear in rejecting anything which artificially prolongs his life. He would unhesitatingly reject the striking artificiality of parenteral feeding. This is clear both from his Advance Directive document and in his mother's evidence. In the exercise of his personal autonomy he is entitled to take that decision which this court is required to and does respect. Accordingly, and for these reasons, I consider that the plan advanced by Dr W is in MSP's best interests. It is important that I make it entirely clear that Dr W puts forward this plan only in the event that I conclude that it reflects what MSP would have wanted. Having heard all the evidence, which I regard as compelling and cogent, I am satisfied that the plan accords with MSP wishes and feelings.

47. MSP has endured a decade of serious ill health. The quality of his life and his mobility has desperately reduced. His confidence and self-esteem has been adversely impacted. His capacity to forge and maintain interpersonal relationships has been significantly eroded. He has made a practical, utilitarian calculation that life in these circumstances is not what he wants. In a real sense this is not a case about choosing to die, it is about an adult's capacity to shape and control the end of his life. This is an important facet of personal autonomy which requires to be guarded every bit as jealously for the incapacitous as for the capacitous.
48. Having heard argument, including on behalf of the press, I consider that the anonymity of MSP should be protected for the remainder of his life and for a period of three months following his death. In the particular circumstances of this case and bearing in mind the extent to which MSP wanted to conceal his stoma from the world, I consider this strikes the appropriate balance between the competing Article 10 (ECHR) and Article 8 rights which are engaged and in which both have parity. Ms Dolan recognises the inevitability of the limited duration in which anonymity can be preserved but makes a request to the press to consider whether it would ever be truly necessary, having regard to the public interest, to publish MSP's name or any details which would reveal his identity.